## Medical end-of-life decisions in the context of terminal care

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Medical end-of-life decisions & terminal care

J-J Georges

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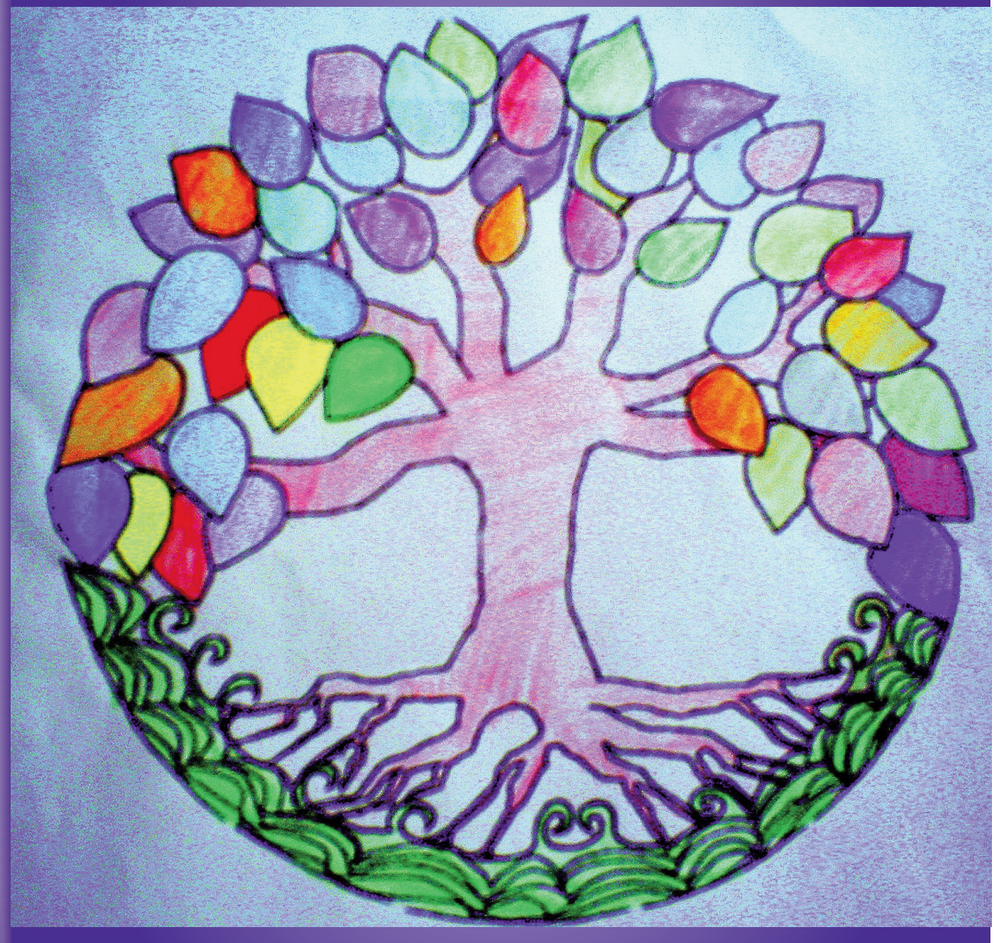

Jean-Jacques Georges

***Uitnodiging***

***tot het bijwonen van de openbare verdediging van het proefschrift van Jean-Jacques Georges***

***op maandag 11 december 2006 om 10.45 uur in het auditorium van de Vrije Universiteit De Boelelaan 1105 te Amsterdam***

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# *Medical End-of-Life Decisions*

# *in*

# *the Context of Terminal Care*

The study presented in this thesis was performed at the Institute for Research in Extramural Medicine (EMGO Institute) at the Department of Public and Occupational Health of the VU University Medical Centre in Amsterdam, the Netherlands, in collaboration with the Department of Public Health of the Erasmus MC in Rotterdam. The EMGO Institute participates in the Netherlands School of Primary Care Research (CaRe), which has been acknowledged by the Royal Dutch Academy of Sciences (KNAW).
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# Medical end-of-life decisions in the context of terminal care

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad Doctor aan
de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
prof.dr. L.M. Bouter,
in het openbaar te verdedigen
ten overstaan van de promotiecommissie
van de faculteit der Geneeskunde
op maandag 11 december 2006 om 10.45 uur
in het auditorium van de universiteit,
De Boelelaan 1105

door

**Jean-Jacques Georges**

geboren te Arlon, België

| | |
|---|---|
| promotoren: | prof.dr. G. van der Wal<br>prof.dr. P.J. van der Maas |
| copromotoren: | dr. B.D. Onwuteaka-Philipsen<br>dr. A. van der Heide |

# Contents

# *Chapter 1*

# *Introduction*

## 1.1 Background of the study

*Terminal care*

A prolonged life-expectancy, the increasing burden caused by chronic illnesses, the pattern of death changing from a sudden, acute episode to a longer process of dying accompanied by physical and mental deterioration, have lead to an increase in the attention that is paid to improving the quality of the end-of-life of patients.[1-4]

Major initiatives directed at improving terminal care have taken place during recent decennia in western countries, such as the development of palliative care services and hospices.[1] Attention has been paid to the treatment of symptoms and care for the specific needs of terminally ill patients and their families in a comprehensive approach, providing physical, emotional, social and spiritual care.[5, 6]

Developments in the care that is provided for terminally ill patients have been encouraged across the world by the World Health Organization (WHO), whose views are reflected in a widely used definition of palliative care:[7]

*'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'*

During recent decades notable developments in care for terminally ill patients have taken place in the Netherlands, e.g. the opening of the first hospice at the beginning of the 1990.[8] The Dutch government has encouraged these developments by providing financial resources to establish six centres for the development of palliative care. The main task of these centres was to enhance the co-ordination of the care, to develop the expertise of care-givers, and to carry out research. Furthermore, collaboration between different palliative care services has been encouraged through integration of the existing hospices within the mainstream health care system, the development of regional networks, and the creation of possibilities to fund scientific research.[8,9] These initiatives have encouraged both the development of knowledge about symptoms and health problems in the terminally ill, and the actual care that is provided for terminally ill patients.[8]

*Medical end-of-life decisions in the perspective of terminal care*

Medical end-of-life decisions, such as forgoing potential life-prolonging treatment, alleviation of pain and symptoms with highly dosed opioids or comparable drugs, terminal sedation, physician-assisted suicide and euthanasia (EAS)†, mainly occur within the context of a terminal illness.[10-13] Earlier studies have shown that in several European countries medical end-of-life decisions that could potentially shorten a patient's life are taken before 23% to 51% of all deaths.[14] Medical end-of-life decisions have been described as a medical response to the suffering of patients, and are related to the estimated life-expectancy of the patient and the patient's wishes.[10, 11]

However, even if these decisions might help to lessen the suffering of a terminally ill patient and to support or enhance the quality of the end of life, both in the Netherlands and abroad, attention has mainly focused on the acceptability of these decisions, especially with regard to EAS.[8] It is often suggested that by assuring high quality terminal care it should be possible to prevent a patient from making a request for EAS, or that by first paying attention to the regulation of the medical practice of EAS, physicians might be less creative in searching for alternative solutions when striving to prevent or to lessen the suffering of a terminally ill patient.[1, 6, 8, 9, 15]

It remains questionable whether, and in which way, approaching palliative care and EAS as two opposite entities contributes to the quality of care and of the quality of the end-of-life of a terminally ill patient. The Dutch former Minister of Health, by eloquently expressing her opinion about the relationship between palliative care and euthanasia indicated the complexity of this issue in the following way:[16]

*'It is certainly so that at times, in the context of extremely severe suffering, good palliative care, adequate pain treatment and a familiar surrounding can shift the borders for a request to have euthanasia carried out and can at times even prevent a request. In other cases, euthanasia can be a dignified end of good palliative care in the final, terminal phase'.*

† In this study the different aspects related to euthanasia and physician assisted-suicide are combined, since they are both directed at intentionally hastening the death of a patient on his/her request.

From this perspective euthanasia is an intervention that is not incompatible with palliative care. Most physicians in the Netherlands consider euthanasia under certain conditions as a possible option within the context of palliative care.[13,17] In the American state of Oregon, since the legalisation of physician-assisted suicide it has been observed that physicians have improved their knowledge and skills with regard to palliative care.[18] Furthermore, study results in the Netherlands have indicated that terminally ill patients and their relatives underline the importance of a broad range of aspects related to terminal care, such as the treatment of pain, communications, and emotional support, and that they also underline the need to be well-informed about medical end-of-life decisions and to be able to talk about their wishes concerning those decisions.[19]

In order to develop terminal care further it is necessary to gain insight into the wishes of patients with regard to medical end-of-life decisions and the way in which medical end-of-life decisions contribute to (the quality of) the end-of-life of terminally ill patients.[1, 11, 15, 20]

### 1.2. Objectives of the study

The objectives of the present study were to gain more insight into medical end-of-life decisions, especially EAS, within the context of terminal care.[13]

We addressed the health problems, symptoms, and concerns of terminally ill patients, and their reasons for requesting medical end-of-life decisions, especially EAS, as well as the treatment of symptoms, the care, and the attitudes and experiences of physicians with regard to terminal care and medical end-of-life decisions. The following study questions were formulated:

1. What are the (health) problems that terminally ill (cancer) patients encounter, during the final months of their life, and how are they treated and cared for?

2. Which wishes related to medical end-of-life decisions, and more specifically with regard to euthanasia and physician-assisted suicide do terminally ill (cancer) patients have? Which factors are related to the development of these wishes?

[13] The term ´terminal care´ will further be used to designate the care provided for patients who are suffering from an illness that can not be cured and whose life-expectancy is limited to a number of months only.

3. What are physicians´ attitudes and experiences with regard to terminal care and medical end-of-life decisions, especially concerning euthanasia and physician-assisted suicide?

### 1.3 Methods

The thesis is based on several (sub)-studies that were designed within the context of the third nationwide study of medical end-of-life decisions and the evaluation of the notification procedure that took place in the Netherlands in 2000-2001. These studies were mainly directed at gaining insight into the experiences and attitudes of terminally ill patient's, as well as the experiences and attitudes of physicians with regard to terminal care and medical end-of-life decisions:

A physician interview study among a random sample of general practitioners (n= 125), nursing home physicians (n= 77), and clinical specialists (n= 208). Physicians were retrospectively interviewed in 2001 by trained physicians about their experiences with regard to requests for EAS from terminally ill (cancer) patients and terminal care.

A prospective study based on a questionnaire that was filled in by the attending physicians of terminally ill cancer patients (n= 85) to describe the patient's symptoms and concerns, the treatment of the symptoms, the care provided for the patient, the patient's requests concerning medical end-of-life decisions, and the attending physician's decision with regard to the patient's request. (See Appendix)

A study based on interviews with relatives of patients who died after their request for EAS had been granted (n= 87). The aim of this study was to assess the experience of the terminally ill patient and the way in which EAS had contributed to the quality of the end-of-life of the patient.

A qualitative study based on interviews with general practitioners (n= 31) about their experiences and attitudes with regard to terminal care and EAS.

A study based on questionnaires to investigate the experiences and opinions of the members of the Euthanasia Review Committees (ERCs) (n= 35) concerning terminal care and EAS.

In the various chapters the methods will be described in more detail.

### 1.4 Content of the thesis

Chapter 1 provides the background information, and describes the objectives and the methods of the various studies.

Chapter 2 presents the results of the prospective study concerning the symptoms of terminally ill cancer patients during the final months of their life until the moment of death, the treatment of the symptoms during this period, the (para-)medical disciplines and the informal carers involved in the care that is provided for the patient, and the dying process.

Chapter 3 presents the results of the prospective study describing the background and the reasons for terminally ill cancer patients' requests to actively hasten death, and also the reasons for forgoing life-sustaining treatment. Factors and circumstances that influence the patients' requests are described, and also the factors related to the attending physician's decision-making process.

Chapter 4 describes the differences between terminally ill cancer patients who died after their request for EAS had been granted and terminally ill cancer patients who did not request EAS. Determinants of EAS, e.g. the symptoms, the treatment of the symptoms, and the care provided, are described.

Chapter 5 mainly describes how requests for EAS had developed and how EAS had contributed to the quality of the end-of-life and the dying of terminally ill patients whose request for EAS had been granted. The data were gathered during interviews with close relatives of patients who died after EAS.

Chapter 6 describes the experiences and attitudes of general practitioners with regard to terminal care and requests for euthanasia on the basis of data obtained from qualitative interviews.

Chapter 7 presents the results of a survey among physicians, relatives of patients and members of the ERCs, investigating factors related to their opinions with regard to terminal care and euthanasia.

In chapter 8 the main methodological aspects of the studies are considered, and the major findings are discussed. The conclusions are summarized, the implications for the further development of policy and practice are discussed, and recommendations are made for further research on terminal care.

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*Chapter 2*

# *Symptoms, treatment and `dying peacefully´ in terminally ill cancer patients: a prospective study*

*Jean-Jacques Georges, Bregje D. Onwuteaka-Philipsen, Agnes van der Heide, Gerrit van der Wal, Paul J. van der Maas*

*Supportive Care in Cancer 2005, 13:160-168*

## Abstract

*Goals*

The aims of this study were to describe the symptoms, their treatment during the final months of life of terminally ill cancer patients and to assess characteristics of the dying process.

*Patients and methods*

We used a prospective study design. From a representative sample of physicians who participated in a study of end-of-life decision making, we asked whether they were treating a patient with cancer whose treatment was no longer aimed at cure, whose life expectancy was probably longer than 1 week but no longer than 3 months and who would probably continue to be treated by the same physician until their death; 85 physicians completed a monthly questionnaire until patients' deaths.

*Results*

Patients were confronted with an increasing amount of symptoms during the final months of their life. Fatigue, loss of appetite, dependency and feeling unwell were the most prevalent symptoms. Physical symptoms were more often treated than psychosocial symptoms. The number of medical disciplines involved in the patient's care decreased in the period before death, but the number of informal caregivers increased; 73% of patients died peacefully. A peaceful death was impeded by feelings of anxiety and loneliness but promoted by the involvement of children in their patients' care.

*Conclusion*

The results give insight into the nature of suffering and factors related to the dying process of terminally ill cancer patients. Attention to psychosocial well-being and to the need to be with loved ones appears to be essential for patients' quality of life.

**Introduction**

Promoting a peaceful death is one of the central purposes of palliative care.[1,2] The need to explore more specifically how to improve care for the dying has been expressed regularly in recent years.[3-8] The concept of dying peacefully is surrounded by a lack of accuracy, and it is not always clear what dying peacefully means to patients and their families or how healthcare may contribute to a peaceful death.[9-12]

The final period in the life of terminally ill cancer patients is impaired by the consequences of problems and symptoms related to the malignancy and to treatment, adding to the burden caused by co-morbidity. Furthermore, because of the prospect of their approaching death, these patients have to cope with psychosocial and existential problems.[13]

Studies on the quality of life of terminally ill cancer patients have described the inter-related influence of these factors on the patient's well-being.[1,14] The process of deterioration until death has been described widely, leading to the conclusion that many patients die in pain and with other distressing symptoms.

The objective of this study was to prospectively assess the symptoms of terminally ill patients in the final months of life until the moment of death, the treatment provided during this period and how they die according to their attending physician. Furthermore, we focussed on describing the dying process by assessing to what extent dying peacefully occurs in this population, characteristics of the dying process and factors that may contribute to a peaceful death.

**Methods**

*Study design and recruitment of participants*

As part of a large-scale study on end-of-life decision making in the Netherlands, random samples of physicians stratified for specialty were interviewed. Selection criteria were that the respondents had to be actively practising medicine at the time of the interview and that they had done so the previous 2 years in the registered specialty and in the same place.

Specialties included in this part of the study were general practitioners, nursing-home physicians, surgeons, internists, pulmonologists and neurologists. Together, these specialties attend to 95% of all deaths in The Netherlands. Of the 434 eligible physicians, 87% agreed to be interviewed (*n*= 376: 174 medical

specialists, 125 general practitioners, 77 nursing home physicians).[15]

Experienced physicians who were extensively trained to use structured questionnaires conducted the interviews. The interview schedule addressed experiences and attitudes concerning end-of-life decision making.

The interview was the starting point for a prospective study on end-of-life care and medical decisions in cancer patients. During the interview, physicians were asked whether at that moment they were treating a patient with the following characteristics: a diagnosis of cancer, whose treatment was no longer directed at cure, whose life expectancy was probably longer than 1 week but no longer than 3 months, and who would probably continue to be treated by the same physician until death. Physicians who were treating such a patient were interviewed about the patient, and at the end of the interview, they were asked to participate in a follow-up study by completing a short questionnaire each month until the patient's death. When consenting to participate, physicians were asked to assign a code to the included patient and to write it on a private reminder with the name of the patient. This code was mentioned on each questionnaire and on a cover letter also mentioning patient's gender, age, primary cancer site and site diagnose. In this way, anonymity of the patient was assured, and physicians were directed on reporting about the same patient during the whole follow-up.

*Measurement instruments*

The interview guide and the written questionnaire were developed specifically for this study and reviewed by three physicians with expertise in research on terminally ill patients. The questionnaire included similar questions to those asked during the interview and was designed in such a way that it would not take more than 15 min to complete. The questions concerned the patient's medical status, symptoms at the time of the physician's last visit, treatment aim, (para-) medical disciplines involved in the treatment and possible wishes of the patient concerning end-of-life decisions. The last questionnaire that was completed shortly after the patient's death also contained questions about any end-of-life decisions taken by the physician and the patient's death.

*Study population*

Of the 376 physicians interviewed, 120 had at the moment of the interview a patient who met the inclusion criteria;

35 (29%) were unwilling to participate or dropped out during the follow-up period. A total of 85 (71%) physicians completed the follow-up. There were no differences between physicians who met the inclusion criteria and physicians who did not with regard to age, gender and belief. However, the first category were more often general practitioners ($P$= 0.006) or medical specialists who specialised in internal medicine ($P$= 0.033) or lung disease ($P$< 0.001). There were no differences with regard to the background characteristics (described in Table 1) between physicians and the number of symptoms at the moment of inclusion (described in Fig. 1) between patients who dropped out during the study and the 85 participants who went on until the death of the patient. However, the primary cancer site was more often a brain tumor in patients who dropped out than in patients included in the follow-up until death (respectively 3/35 and 1/85, $P$= 0.041).

For the majority of the patients for whom follow-up was complete, the survival period was short: 41% died within 1 month after the interview, 25% died between 1 and 2 months later, 12% died between 2 and 3 months later and 22% died between 3 and 6 months later. For this reason, for more than half of the patients, it was only possible to collect data on the moment of inclusion and the moment of death. Therefore, the analysis focused on the time of the interview (inclusion) and the time shortly before death (data from the last questionnaire that was completed shortly after the death of the patient).

In order to gain insight into physician knowledge of a patient's situation, we asked in each questionnaire how many times he or she had visited the patient since completing the last questionnaire. Data from the last completed questionnaire indicated that the mean number of physician visits in the period before a patient's death was 3.97 (±2.490). The median period between the last visit the patient's death was 1 day (range 0–92); 38% of the physicians visited the patient for the last time on the day of the patient's death and 19% on the day (calendar date) before the patient's death.

| Table 1 Characteristics of physicians and patients (n=85) | | n | % |
|---|---|---|---|
| | | | |
| Physicians | | | |
| Age | <40 years | 12 | 14 |
| | 40–49 years | 40 | 47 |
| | 50–59 years | 31 | 36 |
| | ≥ 60 years | 1 | 1 |
| Gender | Male | 60 | 71 |
| | Female | 25 | 29 |
| Religious beliefs | Yes | 33 | 39 |
| Specialty | General practitioner | 34 | 40 |
| | Nursing home physician | 14 | 16 |
| | Clinical specialist | 37 | 44 |
| Patients | | | |
| Age | <45 years | 4 | 5 |
| | 45–60 years | 16 | 19 |
| | 60–75 years | 41 | 48 |
| | >75 years | 24 | 28 |
| Gender | Male | 46 | 54 |
| | Female | 39 | 46 |
| Primary cancer site[1] | Gastrointestinal tract | 27 | 32 |
| | Respiratory system | 25 | 29 |
| | Haematological | 11 | 13 |
| | Breast | 10 | 12 |
| | Genitourinary system | 5 | 6 |
| | Gynaecological | 4 | 5 |
| | Primary tumour unknown | 4 | 5 |
| | Other | 3 | 4 |
| Co-morbidity | Yes | 43 | 51 |
| | Heart disease | 13 | 15 |
| | Chronic obstructive pulmonary disease (COPD) | 9 | 11 |
| | Neuro-psychological problems | 8 | 9 |
| | Diabetes mellitus | 7 | 8 |
| | Geriatric disease/deterioration due to old age | 4 | 5 |
| | Infections | 2 | 2 |
| | Other | 9 | 11 |
| | | | |

| Table 1 Characteristics of physicians and patients (n=85) | | n | % |
|---|---|---|---|
| | | | |
| Time of cancer diagnosis | <1 year ago | 43 | 51 |
| | 1–5 years ago | 33 | 39 |
| | >5 years ago | 9 | 10 |
| Aim of treatment after diagnosis[2] | Curative | 38 | 45 |
| | Life-prolonging | 21 | 25 |
| | Palliative | 32 | 38 |
| Social/ family circumstances[3] | Good social network | 60 | 71 |
| | Many interests | 26 | 31 |
| | Many leisure activities | 17 | 20 |
| | Good family situation | 46 | 55 |

[1]Total more than 100% because three patients had more than one primary cancer site
[2]Total more than 100% because for some patients, more than one aim was mentioned
[3]Measured on a 5-point scale: here the scores '1' (good or many) are presented

*Statistical analysis*

Descriptive statistical analysis was performed on physician and patient characteristics and the prevalence of several variables. Symptoms were assessed on a 5-point Likert scale (1= absence of symptom to 5= presence of symptom with maximum severity). Scores of 2 and 3 were defined as moderate and scores of 4 and 5 as severe. Paired *t* tests were performed in order to assess changes in average of symptoms between the two moments, the Wilcoxon signed ranks test was used to assess changes in the prevalence of symptoms between the two moments and the McNemar test was applied to the treatment of symptoms and number of disciplines involved at the two moments.

The dying process was assessed by asking physicians to evaluate certain descriptive characteristics of the dying process on a 3-point scale (1= fully present, 2= moderately present, 3= not present). One of these characteristics was 'dying peacefully'. No further description of these characteristics was given. Logistic regression was used to identify predictive factors for dying peacefully. Possible predictors were first tested univariately, after which the significant variables were entered into the model in two blocks and removed when not significant. This was done in several ways to check whether there

would be any change in the model. The length of the survival period after the moment of inclusion was also included in the analysis.

**Results**

Table 1 shows characteristics of physicians and the patients who completed the follow-up study. These were similar to the characteristics of the total population (data not shown).

*Suffering*

Prevalence and severity of symptoms at the moment of inclusion and shortly before death are presented in Table 2. Results of the Wilcoxon signed ranks test showed that two symptoms—nausea and coping problems—were less prevalent and/or severe shortly before death than at the moment of inclusion.

Deterioration in the patient's condition was found for 14 symptoms. Some of these were already highly prevalent at the time of inclusion, e.g. fatigue, ADL dependency, feeling unwell, loss of appetite. Others were not, e.g. pressure ulcer, problems with swallowing, dry mouth and urinary and faeces incontinence. With regard to psychosocial symptoms, confusion, unclear consciousness, depressive feelings, feelings of guilt and feelings of loneliness were aggravated shortly before death. This appeared to be more the case for the prevalence of these symptoms than the severity, except for confusion and unclear consciousness.

Shortly before death, the patients suffered from more symptoms than at the moment of inclusion, and they had more severe symptoms (Fig. 1). The mean number of (severe) physical symptoms increased more than the mean number of(severe) psychosocial symptoms before death.

Furthermore, more than 40% were suffering from one or more medical complications at the moment of inclusion and shortly before death. At the moment of inclusion, the most prevalent complications were related to the tumour (*n*= 21/39, e.g. peritonitis carcinomatosa), the circulatory system (*n*= 8/39, e.g. thrombosis) and infections (*n*= 7/39, e.g. abscess). Shortly before death, the most prevalent complications were related to the tumour (*n*= 12/35), the gastrointestinal tract (*n*= 8/35, e.g. intestinal obstruction) and mental problems (*n*= 8/35, e.g. delirium) (data not shown).

Table 2 Prevalence and severity of symptoms[1] (n=85)

| Symptoms | Moment of inclusion | | | | Shortly before death | | | | P value |
|---|---|---|---|---|---|---|---|---|---|
| | n | % | n | % | n | % | n | % | |
| | Moderate | | Severe | | Moderate | | Severe | | |
| Physical | | | | | | | | | |
| Pain | 39 | 46 | 23 | 27 | 45 | 53 | 14 | 17 | |
| Pressure ulcer | 7 | 8 | 4 | 5 | 20 | 24 | 4 | 5 | * |
| Nausea | 33 | 39 | 18 | 20 | 32 | 38 | 9 | 11 | * |
| Vomiting | 17 | 20 | 8 | 9 | 17 | 20 | 5 | 6 | |
| Coughing | 30 | 35 | 14 | 17 | 32 | 38 | 7 | 8 | |
| Dyspnea | 30 | 35 | 15 | 17 | 33 | 39 | 22 | 26 | |
| Problems with swallowing | 14 | 17 | 13 | 15 | 27 | 32 | 17 | 20 | * |
| Dry mouth | 18 | 21 | 10 | 12 | 34 | 40 | 18 | 21 | * |
| Loss of appetite | 26 | 31 | 49 | 58 | 10 | 12 | 68 | 81 | ** |
| Problems with sleeping | 37 | 44 | 17 | 20 | 34 | 41 | 13 | 16 | |
| Constipation | 30 | 35 | 17 | 20 | 40 | 48 | 14 | 17 | |
| Urinary incontinence | 8 | 10 | 5 | 6 | 20 | 24 | 8 | 10 | * |
| Faeces incontinence | 10 | 12 | 4 | 5 | 19 | 23 | 7 | 8 | * |
| Odour | 10 | 12 | 7 | 8 | 19 | 23 | 7 | 8 | |
| Fatigue | 16 | 19 | 65 | 77 | 9 | 11 | 71 | 85 | ** |
| Dependency daily activities | 26 | 31 | 40 | 37 | 11 | 13 | 69 | 82 | ** |
| Feeling unwell | 30 | 35 | 51 | 60 | 18 | 22 | 63 | 75 | ** |
| Psychosocial | | | | | | | | | |
| Coping problems | 35 | 42 | 32 | 38 | 43 | 51 | 14 | 17 | ** |
| Confusion | 11 | 13 | 6 | 7 | 27 | 32 | 13 | 15 | ** |
| Unclear consciousness | 10 | 12 | 3 | 4 | 24 | 29 | 26 | 31 | ** |
| Depressive feelings | 36 | 42 | 5 | 6 | 36 | 43 | 6 | 7 | * |
| Anxiety | 42 | 49 | 18 | 21 | 36 | 43 | 15 | 18 | |
| Feelings of guilt | 13 | 16 | 2 | 2 | 23 | 27 | 1 | 1 | * |
| Feelings of loneliness | 18 | 22 | 4 | 5 | 27 | 32 | 4 | 5 | * |
| Feelings of powerlessness | 41 | 49 | 23 | 28 | 40 | 48 | 21 | 25 | |
| Do not accept dependency | 32 | 31 | 21 | 25 | 31 | 37 | 24 | 29 | |
| Meaninglessness | 28 | 35 | 10 | 13 | 39 | 46 | 10 | 12 | |

[1]Measured on a 5-point scale: 1: absence of symptoms, 2–3: moderate, 4–5: severe

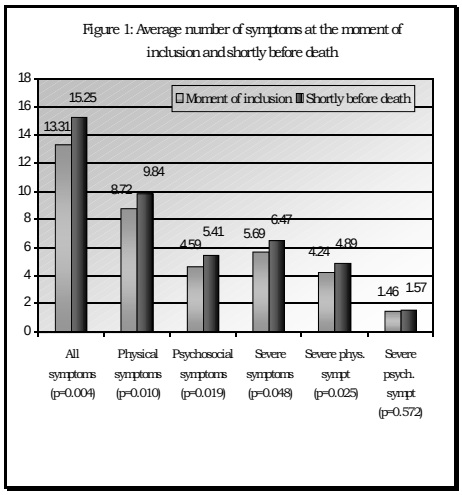
*$P$<0.05 **$P$ ≤0.001

*Treatment of symptoms*

Concerning the specific treatment of symptoms, physicians were asked whether, on the occasion when they last visited the patient before the interview or completed the questionnaire, a new treatment was initiated, an existing treatment was continued or the symptoms in question were not treated. Table 3 shows the prevalence of symptoms in several degrees of severity and for each degree the prevalence of treatment. If treatment was mentioned but the symptom was not present, it was considered that the symptom had been treated successfully. Although the differences in the number of symptoms treated at both moments were not outstanding, some observations could be mentioned. At both moments, severe pain was nearly always treated, and moderate pain was treated in more than 82% of the cases. Nausea was treated in 66% of the cases when moderate and in 88% of the cases when severe at the moment of inclusion.

Shortly before death, moderate nausea was less often treated while severe nausea was treated in all cases. The treatment of dyspnoea was similar at both moments; 40% of the patients with moderate dyspnoea and 80% with severe dyspnoea were treated. Depressive feelings were not treated very often at the time of inclusion, even if severe, but they were treated slightly more often shortly before death.

Moderate and severe anxiety was treated in 29% and 38% of patients at the time of inclusion, and this increased slightly to 31% and 46%, respectively, shortly before death. Confusion was also treated more often shortly before death than at the time of inclusion, especially if the symptoms were severe.




Because psychosocial symptoms were treated less often than physical symptoms, the involvement of professionals from psychosocial disciplines, such as psychiatrists, psychologists or pastors, with patients suffering from these symptoms was investigated. No change was found in their involvement.

*Disciplines involved*

Table 4 shows that the number of some professionals from (para-) medical disciplines, such as internists/oncologists or radiation therapists, involved in the treatment of patients in addition to the attending physician decreased shortly before death. Professionals from specific palliative care disciplines, such as pain specialists and palliative care specialists, were only involved in the treatment of a minority of patients and slightly more often shortly before death. An identical pattern was observed for the involvement of psychologists and psychiatrists. Pastors, too, were also only marginally involved, even shortly before death. The contribution of nurses and (intensive) home care providers was high at the moment of inclusion and increased shortly before death. Informal carers were very often involved in caring for the patient. Their involvement was increased between the moment of inclusion and shortly before a patient's death. The patient's partner and children were most often involved as informal carers.

Table 3 Specific treatment of symptoms according to severity at the moment of inclusion and shortly before death[1] (n=85)

| Severity of symptoms | Prevalence | Treatment, moment of inclusion | | Prevalence | Treatment, shortly before death | |
|---|---|---|---|---|---|---|
| | n | n | % | n | n | % |
| Pain | | | | | | |
| No | 21 | 7 | 33 | 26 | 17 | 65 |
| Moderate | 39 | 32 | 82 | 45 | 41 | 91 |
| Severe | 23 | 22 | 96 | 14 | 14 | 100 |
| Nausea | | | | | | |
| No | 34 | 2 | 6 | 44 | 12 | 27 |
| Moderate | 33 | 22 | 66 | 32 | 15 | 47 |
| Severe | 18 | 16 | 88 | 9 | 9 | 100 |
| Dyspnea | | | | | | |
| No | 40 | 1 | 2.5 | 30 | 7 | 23 |
| Moderate | 30 | 12 | 40 | 33 | 14 | 42 |
| Severe | 15 | 12 | 80 | 22 | 18 | 81 |
| Depressive feelings | | | | | | |
| No | 44 | 2 | 5 | 38 | 0 | 0 |
| Moderate | 36 | 3 | 8 | 36 | 6 | 16 |
| Severe | 5 | 0 | 0 | 6 | 2 | 33 |
| Anxiety | | | | | | |
| No | 25 | 0 | 0 | 32 | 5 | 16 |
| Moderate | 42 | 12 | 29 | 36 | 11 | 31 |
| Severe | 18 | 7 | 38 | 15 | 7 | 46 |
| Confusion | | | | | | |
| No | 68 | 1 | 1.4 | 43 | 2 | 5 |
| Moderate | 11 | 3 | 27 | 27 | 9 | 33 |
| Severe | 6 | 2 | 33 | 13 | 10 | 77 |

[1]Differences in the number of symptoms treated at both moments were not significant for any symptom when symptoms were moderate and severe

Table 4 Number and type of care-givers involved in the treatment/care at the moment of inclusion and shortly before death (n=85)

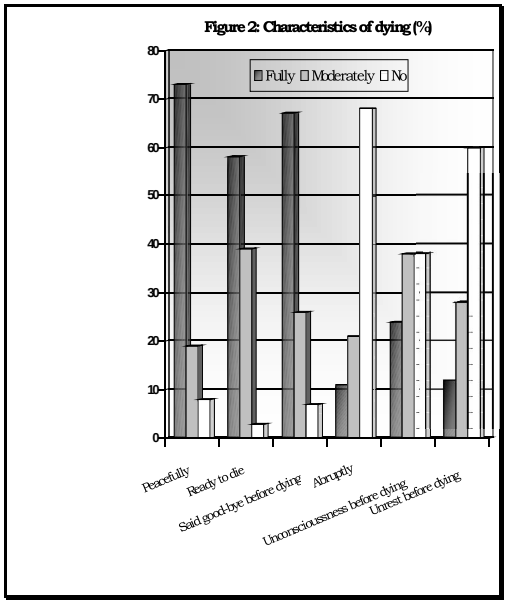
| | Moment of inclusion | | Shortly before death | | P value[1] |
|---|---|---|---|---|---|
| | n | % | n | % | |
| (Para-)medical disciplines | | | | | |
| Internist/oncologist | 37 | 44 | 23 | 27 | * |
| Radiation therapist | 17 | 20 | 8 | 9 | * |
| Pain specialist | 2 | 2 | 3 | 4 | |
| Neurologist | 6 | 7 | 6 | 7 | |
| Surgeon | 7 | 8 | 7 | 8 | |
| Palliative care specialist[1] | 2 | 2 | 9 | 11 | * |
| Psychiatrist/psychologist | 6 | 7 | 3 | 4 | |
| Nurse | 43 | 51 | 60 | 71 | * |
| Wound/stoma care specialist | 5 | 6 | 2 | 2 | |
| Nursing technology specialist[1] | 2 | 2 | 8 | 9 | * |
| (Intensive) Home care provider | 9 | 11 | 23 | 27 | |
| Social worker | 7 | 8 | 3 | 4 | |
| Physiotherapist | 12 | 14 | 8 | 9 | |
| Dietician | 14 | 17 | 6 | 7 | |
| Pastor | 17 | 20 | 23 | 27 | |
| Alternative healer | 3 | 4 | 2 | 2 | |
| Volunteer | 3 | 4 | 10 | 12 | |
| Other | 23 | 27 | 9 | 11 | * |
| Mean number of medical disciplines | 2.52 | | 2.50 | | |
| Informal care-givers | 71 | 84 | 79 | 93 | |
| Partner | 55 | 65 | 59 | 69 | |
| Parents | 2 | 2 | 2 | 2 | |
| Children | 36 | 42 | 56 | 66 | ** |
| Other relatives | 7 | 8 | 26 | 31 | * |
| Friends | 11 | 13 | 17 | 20 | |
| Other | 1 | 1 | 3 | 3 | |
| Mean number of informal care-givers | 1.31 | | 1.90 | | ** |

[1] *P* value could be affected by the small number of cases *$P<0.05$ **$P<0.001$

*The dying process*

At the moment of inclusion, 67% of patients were aware of their impending death, and 26% were aware of their terminal illness but not of their impending death; shortly before death, this respectively was 83% and 9%; only in a few cases were patients not aware of their terminal illness (4%) or the physician was not sure about the patient's awareness (4%).

In order to describe the dying process, physicians were asked to rate on a 3-point scale which characteristics were applicable to the death (Fig. 2): 73% died peacefully, 67% said good-bye before dying and 58% were ready to die. Furthermore, 68% did not die abruptly, for 38% there was no period of unconsciousness before death and for 60% there was no period of unrest before death.




*Dying peacefully*

Within the context of the dying process, the determinants of dying peacefully were investigated. Of all variables presented in this paper, the variables that were found to be significant in the univariate analysis are described in Table 5. This table shows that, above all, psychosocial symptoms, but also some other symptoms that may be related to existential problems, such as loneliness, meaninglessness and feelings of guilt, impeded the dying process. Being cared for by loved ones, having said good-bye and being ready to die were positively related to dying peacefully. Finally, in multivariate analysis, only three variables remained significant: i.e. the probability of dying peacefully could be predicted if a patient was not feeling lonely at the moment of inclusion, was not feeling anxious at the moment of inclusion and was being cared for by their own children shortly before death (Table 5).

**Discussion**

The results of this study provide insight into the symptoms of terminally ill cancer patients, their treatment during the final period of their life and their dying process. The most prevalent symptoms in the study population some 1–2 months before death were fatigue, loss of appetite, ADL dependency and feeling unwell, and these symptoms were even more prevalent shortly before dying. Shortly before death, the average number of physical symptoms increased, and a majority of patients were confronted with disturbing symptoms, such as problems with swallowing, dry mouth and incontinence. The psychosocial well-being of most patients was, above all, hampered by coping problems, powerlessness, anxiety and problems with accepting dependency. Confusion and unclear consciousness, which are potentially related to physiological processes, worsened with approaching death while psychosocial problems related to mood, such as coping problems, anxiety and powerlessness, tended to have improved or stabilised shortly before death. Physical symptoms, especially pain, were treated much more often than psychosocial problems. Only a few patients were treated for their depressive feelings, anxiety and confusion at the moment of inclusion, but shortly before death, more attention was paid to these problems, especially when they were rated as severe.

The majority of patients died peacefully according to their physicians. Univariate analysis showed that at the moment of inclusion and also shortly before death, the average number of psychosocial symptoms and some specific symptoms, e.g. anxiety, loneliness and meaninglessness, had a negative effect on the dying process.

On the other hand, being cared for by loved ones (at both moments), having said good-bye and being ready to die were positively correlated with dying peacefully. Finally, multivariate analysis showed that patients who did not feel anxious or lonely in the weeks before death and who were cared for by their children shortly before death had a greater prospect of dying peacefully.

Table 5 Predictive variables of dying peacefully (odds ratios [0R], P values and 95% confidence intervals [CI], (n=71)[1]

| | OR | P value | CI |
|---|---|---|---|
| Univariate analysis | | | |
| Average number of symptoms (M I) | 0.87 | 0.035 | 0.77–0.99 |
| Average number of psychosocial symptoms (MI) | 0.71 | 0.008 | 0.55–0.91 |
| Average number of psychosocial symptoms (SD) | 0.81 | 0.031 | 0.67–0.98 |
| Average number of severe psychosocial symptoms (MI) | 0.75 | 0.046 | 0.57–0.99 |
| Coping problems (MI) | 0.62 | 0.036 | 0.40–0.97 |
| Anxiety (MI) | 0.47 | 0.003 | 0.28–0.78 |
| Anxiety (SD) | 0.52 | 0.004 | 0.34–0.82 |
| Loneliness (MI) | 0.36 | 0.001 | 0.19–0.65 |
| Meaninglessness (MI) | 0.60 | 0.026 | 0.39–0.94 |
| Feelings of guilt (SD) | 0.77 | 0.044 | 0.58–1.01 |
| Average number of medical disciplines (MI) | 0.74 | 0.051 | 0.54–1.00 |
| Being cared for by other relatives (MI) | 6.46 | 0.043 | 1.06–39.39 |
| Being cared for by children (SD) | 2.69 | 0.024 | 1.41–6.37 |
| Having said good-bye | 3.16 | 0.040 | 1.05–9.50 |
| Being ready to die | 3.56 | 0.031 | 1.12–21.28 |
| Dying abruptly | 0.32 | 0.048 | 0.11–0.94 |
| Multivariate analysis | | | |
| Feelings of loneliness (MI) | 0.42 | 0.015 | 0.21–0.84 |
| Anxiety (MI) | 0.49 | 0.024 | 0.26–0.91 |
| Being cared for by children (SD) | 4.26 | 0.034 | 1.12–16.35 |

[1]The variables 'end-of-life wishes' and 'patient's worries' (not shown in this article) were not significant in the univariate analysis [2] MI: variables assessed at the moment of inclusion. [3] SD: Variables assessed shortly before death

The study has some methodological limitations. The limited number of participants to the study restricts the generalisability of the results. However, the physicians were derived from a representative sample of physicians in The Netherlands. Physicians are often too optimistic about the survival period of their patient.[16,17] It is therefore possible that when asked about a patient with an expected survival period not longer than 3 months, physicians participating to our study erroneously did not include a patient. Furthermore, to be included to the follow-up, the patient had to be treated by the physician at the time of the interview. These reasons may explain the low rate of inclusion. The inclusion rate for at least general practitioners and nursing-home physicians seems in line with data about the number of terminally ill cancer patients being attended to yearly by these specialties in The Netherlands.[12]

Another limitation of this study is that the data are based on information provided by the attending physicians. It might therefore be possible that, for instance, dying peacefully has been somewhat over-estimated by the physicians. However, our data about the number of physicians' visits to patients and about the timing of the last visit near death support the accuracy of physicians' assessments.

Similar findings, i.e. a high prevalence of fatigue, ADL dependency and feeling unwell and an increase in the number and severity of physical symptoms shortly before death have been reported for other cancer patients.[14,18-22]

As the study was primarily directed at describing end-of-life care and decisions in terminally ill cancer patients, we could not assess the dying process in more detail nor explore how physicians defined a peaceful death. With regard to the place of death, as patients who were not treated by the attending physician until their death dropped out, it is likely that the place of death of most patients was related to the specialty of the participating physician.

Finally, we have been able to describe the most important factor that had an influence on dying peacefully. It is possible that because of the limited number of participants, some other factors that also influence the dying process did not appear as predictors in multivariate analysis.

The decrease in the number of (para-) medical professionals involved, other

than the attending physician, and the increase in the participation of informal carers shortly before death indicates that care is aimed more at enhancing patient comfort through informal support and attention than is burdening the patient with potentially disturbing medical treatment.

The fact that, according to their attending physician, the majority of the patients, died peacefully is, after all, not surprising because most patients felt ready to die and for months before their death had been aware of their terminal condition; therefore, they had probably prepared themselves for death and said good-bye to their loved ones.

The worsening of a patient' condition shortly before death due to the high number and severity of physical symptoms in particular, did not appear to affect the dying process according to the multivariate analysis. However, this does not imply that physical symptoms are not relevant, because univariate association between dying peacefully and average number of symptoms at the moment of inclusion were found. It is possible that physicians only took a very short period before death into consideration when assessing whether or not the patient died peacefully.

Since anxiety and feelings of loneliness some weeks before death and not shortly before death are predictors of a peaceful death, dying should be considered as a process that begins earlier than when death is imminent. The present results illuminate the concept of dying and might have some important implications with regard to the care for terminally ill patients. In order to promote a peaceful death, it is likely that a great deal of attention must be paid to psychosocial problems and to the patient's needs for social support earlier in the illness trajectory. The multivariate analysis indicates that children and loved ones may be an essential source of comfort for the patient and that they probably have an essential role in helping the patient to come to terms with death. Therefore, when appropriate, their participation in the patient's care should be supported and encouraged by the professionals involved.

From this study we might conclude that even though terminally ill cancer patients are suffering from several symptoms, a majority dies peacefully, according to their attending physician. Psychosocial and relational variables mainly interfere with the dying process. These results have to be

confirmed by other studies focusing primarily on the dying process. In order to describe the concept of 'peaceful dying', studies need to be performed with the several participants confronted with dying patients, e.g. physicians, nurses and relatives, using methods directed at eliciting the unique experience of patients.

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*Chapter 3*

# *Requests to forgo potentially life-prolonging treatment and to hasten death in terminally ill cancer patients: a prospective study*

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**Abstract**

*Goals*

This study investigates the background and evolution of requests to forgo treatment and hasten death in terminally ill cancer patients.

*Patients and methods*

Physicians participating in a nationwide study on end-of-life decision making were asked whether they were treating a terminally ill cancer patient whose life expectancy was longer than 1 week but no longer than 3 months and who they would continue to treat until the patient's death. Of the 120 physicians who had a patient who met the inclusion criteria, 85 (70.8%) completed a questionnaire each month until the patient's death. The questionnaire provided information on the patient's symptoms, concerns, and requests involving end-of-life decisions.

*Results*

Most patients suffered from cancer of the gastrointestinal tract or the respiratory system, and 66% died within 2 months of the initial interview. The prevalence of requests involving end-of-life decisions increased during the last 3 months of a patient's life. The evolution of a request was especially related to an increase in the number of severe symptoms and concerns. Requests to forgo treatment were related to general weakness, whereas loss of dignity was a major reason for requests to hasten death. Physical suffering alone appeared to lead to less drastic requests than suffering blended by concerns and psychological problems leading to requests for hastened death.

*Conclusion*

The results emphasize the importance of gaining insight into the patients' suffering to provide meaningful assistance.

**Introduction**

Patients' attitudes related to medical end-of-life decisions have been described in several groups of terminally ill patients[1-3] and at several stages of the illness trajectory.[4,5] It is through large-scale studies that the characteristics of medical decisions pertaining to the end of life and requests of patients are most often described.[6-11] In these studies, a distinction is made between several types of medical decisions, e.g., euthanasia and physician-assisted suicide, alleviation of symptoms and of pain with large doses of opioids, and decisions to forgo treatment. Studies show that patients who request euthanasia or physician-assisted suicide in comparison to those who request non treatment decisions suffer more often from cancer and are males and younger.[9, 10] It has been observed that requests for euthanasia and physician-assisted suicide are most often related to physical symptoms, such as pain,[12-15] and psychological problems, such as depression, hopelessness, and meaninglessness.[13,14,16-22] However, reasons related to personality and relationships with others, e.g., frustration about their own life and feelings of being a burden on others, have also been described.[3,14,18,21,23,24]

Reasons underlying terminally ill patients' requests to forgo treatment have been related to treatment burden, treatment outcome, and to the likelihood of the outcome.[25] However, because only limited attention has been given to elicit terminally ill patient's reasons to forgo treatments,[25,26] it is hard to clearly differentiate between factors that are related to requests to hasten death and to forgo treatment. Nevertheless, to support terminally ill patients and to contribute to their quality of life, it is essential to fully understand the reasons for their choices concerning end-of-life decisions and to gain insight into factors related to their choices.[23-27]

This study focuses on terminally ill cancer patients' requests to forgo treatment and to hasten death. By describing the reasons for their request, their symptoms and concerns at several points in time, and also the situation of those patients who did not make any requests, an attempt is made to provide more insight into specific factors and circumstances influencing patients' requests pertaining to medical end-of-life decisions. The decisions made by physicians, and their opinions

about these requests, were also investigated.

**Methods**

*Participants and Procedure*

As a part of a large-scale study on end-of-life decision making in The Netherlands, random samples of physicians, stratified for specialty, were interviewed. The selection criteria were that the respondents had to be actively practicing medicine at the time of the interview and that they had done so the previous 2 years in the registered specialty and in the same place. The medical specialists included in this part of the study were general practitioners, nursing home physicians, surgeons, internists, pulmonologists, and neurologists. Together, these medical specialists attend to 95% of all deaths in The Netherlands. Of the 434 selected physicians, 87% agreed to be interviewed (n=376: 174 medical specialists, 125 general practitioners, and 77 nursing home physicians).[9]

Experienced physicians, extensively trained to use the structured questionnaires, conducted the interviews. The interview schedule addressed experiences and attitudes concerning end-of-life decision making. Further details about this large-scale study have been described elsewhere.[9] The interview was the starting point for a prospective study on end-of-life care and medical decisions in cancer patients. During the interview, the physicians were asked whether they, at that moment, were treating a patient with the following characteristics: a patient with a diagnosis of cancer, whose treatment was no longer directed at cure, whose life expectancy was probably longer than 1 week but no longer than 3 months, and who would probably continue to be treated by the same physician until death. Of the 376 interviewed physicians, 120 had a patient who met the inclusion criteria at the time of the interview. They were interviewed about the patient and they were asked to participate in the follow-up by completing a short questionnaire each month until the patient's death. When consenting to participate, physicians were asked to assign a code to the included patient and to write it on a private reminder with the name of the patient. This code was mentioned on each questionnaire and on a cover letter also mentioning the patient's gender, age, primary cancer site, and comorbid diagnoses. In this way, anonymity of the patient was assured, and physicians were directed to report on the same patient during the whole follow-up.

*Materials*

The interview schedule and the written questionnaire were developed specifically for this study and reviewed by three physicians with expertise in research on and the treatment of terminally ill patients. The questionnaire included questions similar to those that were asked during the interview. The questions concerned the patient's medical status, the patient's symptoms at the time of the physician's last visit, the aim of the treatment, and the patient's concerns and requests related to end-of-life decisions made to the physician since the last time the physician completed a questionnaire on the symptoms, concerns and requests in the care and treatment of that specific patient. The final questionnaire was completed shortly after the patient's death. To gain insight into the physician knowledge of patient's situation, we asked in each questionnaire how many times he or she had visited the patient since the completion of the last questionnaire. Data from the last completed questionnaire indicated that the mean number of physician visits in the period before patient's death was 3.97 (±2.490); 38% of the physicians visited the patient for the last time on the day of the patient's death, 19% on the day (calendar date) before the patient's death, 14% between 2 and 3 days before patient's death, and 11% between 4 and 8 days before patient's death.

A distinction was made between requests to forgo treatment, which included withholding and withdrawing potentially life-prolonging treatment, e.g., refusing food intake, to only be hydrated, and choosing to receive only treatment such as painkillers directed at alleviating symptoms, and requests to hasten death, which included euthanasia and physician-assisted suicide. This distinction not only pertains to potential differences concerning the effect of the shortening of life but also to moral aspects based on the distinction between the concepts of 'allowing dying' and 'causing death intentionally.' Requests for terminal sedation were considered as a separate category, because the number of requests in this category had very low frequencies and is only reported when appropriate.

*Statistical Analysis*

Descriptive statistical analysis was performed on the characteristics of the physicians and the patients, the prevalence of several variables, and the patients' requests. Symptoms were assessed on a 5-point Likert scale (1= absence of symptoms to 5= presence of

symptoms with maximum severity). Scores of 2 and 3 were defined as moderate and scores of 4 and 5 as severe. Pearson's correlation coefficient (two-tailed) was used to assess the relationship between the number of concerns and symptoms, and logistic regression was applied to investigate the predictive variables for a request shortly before death. Nonparametric tests were performed to assess differences between physicians who participated in the follow-up and those who did not, between patients who made no request at all and those who did after the moment of inclusion, and between the reasons for requests to forgo treatment and to hasten death. t-Tests (two-tailed) were performed to assess differences in the number of symptoms and of concerns between the moment of inclusion and shortly before death among several requests, and to assess differences between requests that were granted and those that were not.

**Results**

*Sample Characteristics*

Of the 120 physicians who treated a patient meeting the inclusion criteria, 85 (70.8%) participated in the follow-up until the death of the patient (44% clinical specialists, 40% general practitioners, and 16% nursing home physicians), 13 refused to participate, and 22 dropped out during the follow-up period. There appeared to be no differences between physicians who completed the follow-up and those who did not want to participate or dropped out. However, their patients differed on a few characteristics, including brain as primary cancer site (respectively 1/85 and 3/35, P= 0.041) and 'meaningless suffering' as reason to have a request (data from the moment of inclusion) (respectively, 12/31 and 1/13, P= 0.042). Other available data showed no significant differences between these patients.

Most physicians (83%) were between 40 and 60 years old. Seventy-one percent were male and 39% had a religious belief.

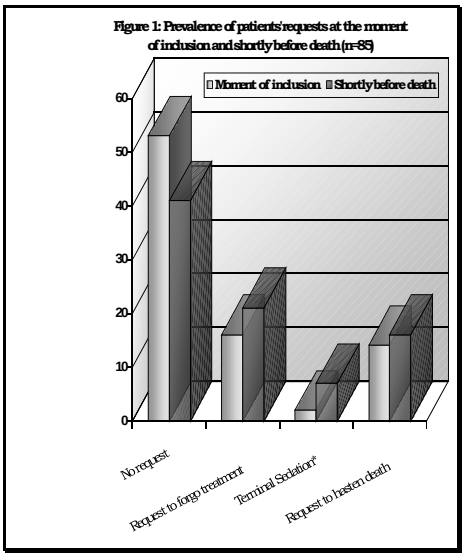
Most patients (67%) were between 45 and 75 years old, 28% were older than 75, and 54% were male. The most frequent primary cancer sites were the gastrointestinal tract (32%), the respiratory system (29%), hematologic (13%) and the breast (12%). Sixty-one percent of the patients had some type of comorbidity. The survival period of the majority of patients was short; 41% died within 1 month of the interview, 25% between 1 and 2 months, 12% between 2 and 3 months, and 22% between 3 and 6 months. For this reason, in more than half of the

patients, it was only possible to collect data at the moment of inclusion and the moment of death. Therefore, the analysis focused on the time of the interview (inclusion) and the time shortly before death.

*Prevalence of Patients' Requests*

Fig. 1 shows the prevalence and evolution of patients' requests at the time of inclusion and shortly before death. At the moment of inclusion, 32 (38%) patients, and shortly before death, 44 (52%) patients made a request for terminal sedation, to forgo treatment or to hasten death. Of the patients who made a request at the moment of inclusion, nine no longer did so shortly before death, whereas 21 patients who made no request at the moment of inclusion did make one shortly before death.

A change in the nature of the request occurred between the two points in time in 36/85 (42%) of the patients. The other patients still made no request (32/85 or 38%) or made the same request (17/85 or 20%) at both points in time. Of the 36 patients who changed their request after the moment of inclusion, 21 (58%) made a request for terminal sedation, to forgo treatment, or to hasten death, but had made no request at the moment of inclusion.




*Information about terminal sedation is reported for the sake of accuracy, but is not included in further statistical analysis*

To gain insight into the factors that might influence the generation of a request, a comparison was made of the demographic characteristics and characteristics related to the illness, diagnosis, and treatment of patients who made no request from the moment of inclusion until their death (n= 32) with those of patients who had expressed a request after the moment of inclusion (n= 21). None of these characteristics appeared to differ significantly between the two groups. It is in relation to the course of the patients' symptoms and concerns that differences between both groups were the most marked. Those who made a request after the moment of inclusion experienced an increase in the average

number of symptoms between the two points in time (mean= 4.21, P= 0.001); there was an increase in physical symptoms (mean= 2.42, P= 0.001) as well as psychosocial symptoms (mean= 1.79, P= 0.019). An increase in the average number of concerns between the two points in time was also observed in this patient group, but it was not statistically significant (mean = 0.44, P= 0.353). In patients who made no request at all the increase in the average number of symptoms was less (mean= 1.78, P= 0.140), and the average number of concerns decreased between the two points in time (mean= −0.58, P= 0.086).

*Reasons for Patients' Requests*

Table 1 presents the patients' reasons for making a request to forgo treatment or to hasten death. The most frequent reasons for making a request to forgo treatment were general weakness (57%) and hopeless suffering (52%). The most frequent reasons for making a request to hasten death were loss of dignity (75%), general weakness (63%), and hopeless suffering (63%). Loss of dignity and loss of control over one's life were significantly more often mentioned in requests to hasten death than in requests to forgo treatment.

*Patients' Requests, Symptoms, and Concerns*

Table 2 describes the symptoms and concerns of patients who made no request and those who requested to forgo treatment or to hasten death shortly before death. The prevalence of fatigue, feeling unwell, pain, problems with accepting dependency, powerlessness, and depressive feelings was higher in patients who had made a request to hasten death than in the other two groups. With regard to concerns, Table 2 shows some interesting differences between the groups. For most concerns, the prevalence was highest in patients who had made a request to hasten death. In patients who had made no request, the lowest prevalence was found for most concerns.

Table 1 Reasons for patients' requests shortly before death (n=37)

| | Request to forgo treatment n=21 | | Request to hasten death n=16 | | Total n=37 | |
|---|---|---|---|---|---|---|
| **Reasons**† | n | (%) | n | (%) | n | (%) |
| General weakness | 12 | (57) | 10 | (63) | 22 | (59) |
| Hopeless suffering | 11 | (52) | 10 | (63) | 21 | (57) |
| Loss of dignity | 4 | (19) | 12 | (75)* | 16 | (43) |
| Meaningless suffering | 7 | (33) | 6 | (38) | 13 | (35) |
| Physical symptoms (pain, nausea, dyspnea) | 4 | (19) | 9 | (56) | 13 | (35) |
| Loss of control over own life | 2 | (9) | 9 | (56)* | 11 | (30) |
| Dependency | 2 | (9) | 6 | (38) | 8 | (22) |
| Fear of physical symptoms (pain, suffocation) | 1 | (5) | 5 | (31) | 6 | (16) |
| Experience of deterioration | 1 | (5) | 4 | (25) | 5 | (14) |
| Weakness after long medical treatment | 3 | (14) | 1 | (6) | 4 | (11) |
| Fear of the dying process | 0 | (0) | 4 | (25) | 4 | (11) |
| Not being a burden for others | 2 | (9) | 1 | (6) | 3 | (8) |
| Tired of life | 1 | (5) | 1 | (6) | 2 | (5) |
| Threat of complications | 0 | (0) | 2 | (13) | 2 | (5) |
| Mean number of reasons (± SD) | 2.52 (± 1.40) | | 4.14 (± 1.610) | | 3.17 (± 1.671) | |
| **Most important reasons for patients** | | | | | | |
| Hopeless suffering | 5 | (24) | 4 | (25) | 9 | (24) |
| General weakness | 6 | (29) | 1 | (6) | 7 | (19) |
| Loss of dignity | - | - | 6 | (38) | 6 | (16) |
| Meaningless suffering | 3 | (14) | - | - | 3 | (8) |
| Loss of control over own life | - | - | 2 | (13) | 2 | (5) |

* $P < 0.05$

†More than one answer possible

Table 2 Patients' severe*symptoms[1] and concerns shortly before death according to the type of request

| | No request n=41 | | Request to forgo treatment n=21 | | Request to hasten death n=16 | | Total n=85 | |
|---|---|---|---|---|---|---|---|---|
| Physical | n | (%) | n | (%) | n | (%) | n | (%) |
| Fatigue | 33 | (87) | 16 | (76) | 16 | (100) | 71 | (87) |
| ADL-dependency | 35 | (88) | 14 | (70) | 13 | (81) | 69 | (83) |
| Loss of appetite | 30 | (75) | 18 | (86) | 14 | (85) | 68 | (81) |
| Feeling unwell | 25 | (64) | 17 | (81) | 15 | (94) | 63 | (77) |
| Dyspnea | 12 | (29) | 3 | (14) | 6 | (38) | 22 | (26) |
| Dry mouth | 9 | (22) | 4 | (19) | 2 | (13) | 18 | (21) |
| Constipation | 8 | (20) | 2 | (10) | 2 | (13) | 14 | (17) |
| Pain | 5 | (12) | 3 | (14) | 5 | (31) | 14 | (17) |
| Psychosocial | | | | | | | | |
| Unclear consciousness | 15 | (38) | 4 | (19) | 3 | (19) | 26 | (31) |
| Accepting dependency | 11 | (29) | 6 | (30) | 3 | (19) | 24 | (30) |
| Powerlessness | 10 | (26) | 4 | (20) | 6 | (38) | 21 | (26) |
| Anxiety | 9 | (23) | 2 | (10) | 3 | (19) | 15 | (18) |
| Coping problems | 8 | (21) | 4 | (19) | 2 | (13) | 14 | (17) |
| Depressive feelings | 3 | (8) | 0 | (-) | 2 | (13) | 6 | (8) |

Table 2 Patients' severe*symptoms and concerns shortly before death according to the type of request

| | No request n=41 | | Request to forgo treatment n=21 | | Request to hasten death n=16 | | Total□ n=85 | |
|---|---|---|---|---|---|---|---|---|
| Concerns§ | | | | | | | | |
| Pain | 11 | (27) | 6 | (28) | 12 | (75) | 34 | (42) |
| Dyspnoea | 6 | (15) | 8 | (38) | 9 | (56) | 28 | (35) |
| ADL-dependency | 7 | (18) | 3 | (14) | 7 | (44) | 18 | (22) |
| Fear dying process | 6 | (15) | 3 | (14) | 3 | (19) | 14 | (18) |
| Loss of dignity | 1 | (3) | 1 | (4) | 11 | (69) | 14 | (17) |
| Fear of death | 5 | (13) | 2 | (9) | 3 | (19) | 11 | (14) |
| Missing important event | 3 | (8) | 2 | (9) | 3 | (19) | 10 | (12) |
| Confusion | 1 | (3) | 2 | (9) | 3 | (19) | 8 | (10) |
| No able to communicate | 3 | (8) | 2 | (9) | 3 | (19) | 8 | (10) |
| Addiction to medicine | 4 | (10) | 1 | (5) | - | - | 6 | (6) |
| Unclear consciousness | 0 | - | 0 | - | 2 | (13) | 2 | (3) |
| Loneliness | 2 | (5) | 0 | - | 0 | - | 2 | (3) |

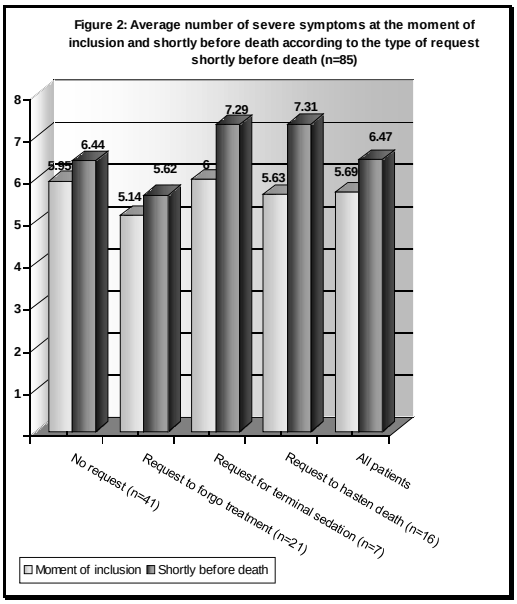
[1] Measured on a 5-point Likert scale: 1 absence of symptoms, 2-3 moderate symptoms, 4-5 severe symptoms † Selection of symptoms with prevalence > 60% in the total population shortly before death □Total includes requests for terminal sedation §4 missing values in total column

Changes in symptoms and concerns between the moment of inclusion and shortly before death are represented in Fig. 2 and Fig. 3, respectively. In all groups the average number of symptoms was the highest shortly before death, with significant differences between the two points in time in requests to hasten death (P= 0.014) (Fig. 2). A higher average number of concerns shortly before death than at the moment of inclusion was only observed in patients who had made a request to hasten death shortly before death (Fig. 3). Shortly before death, patients who had made no

request had significantly fewer concerns than patients who had made a request (P< 0.05), and patients who had made a request to forgo treatment had significantly fewer concerns than patients who had made a request to hasten death at the moment of inclusion (P< 0.005) and shortly before death (P< 0.001).

No significant relationships were found between the number of concerns and any of the 17 physical symptoms that were assessed. Of the10 psychosocial symptoms, 4 were significantly related to the patient's average number of concerns. Significant correlations were found for coping problems (R= 0.324, P= 0.006), depressive feelings (R= 0.283, P= 0.018), feeling of powerlessness (R = 0.384, P= 0.001), and feeling of meaninglessness (R= 0.344, P= 0.004).

Table 3 shows the results of logistic regression applied to determine which factors contributed to the development of a request shortly before death (including requests to forgo treatment and to hasten death). Significant variables were assessed in multivariate analysis, resulting in a model that correctly predicted 73% of the cases. Variables that remained significant were concerns about dyspnoea and concerns about loss of dignity.



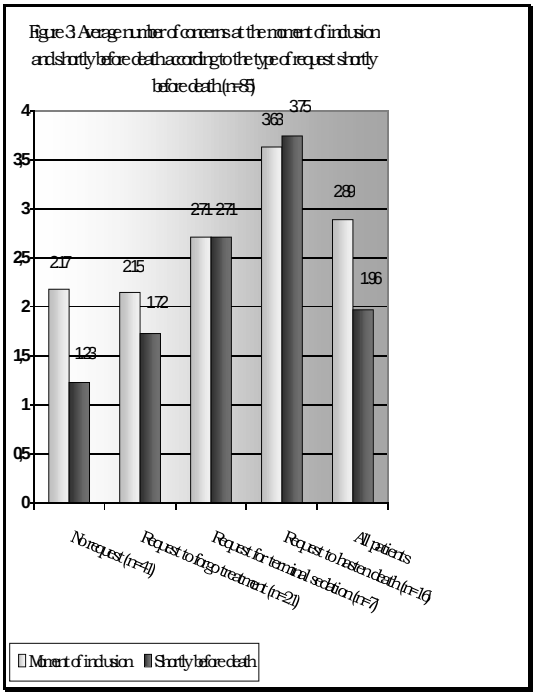



Table 3 Predictive factors for making a request shortly before death (n=78, odds ratio [OR], P-values and 95% confidence intervals [CI])

| | OR | P-value | CI |
|---|---|---|---|
| Univariate analysis* | | | |
| Moment of inclusion | | | |
| Information from physician about forgoing treatment | 3.3 | 0.008 | 1.3 – 8.2 |
| End-of-life request | .9 | 0.005 | 1.5 – 10. |
| Shortly before death | | | |
| Feeling unwell† | 1.7 | 0.04 | 1.0 – 2.8 |
| Concerns about pain | 2.9 | 0.028 | 1.1 – 7.8 |
| Concerns about dyspnea/suffocation | 5.6 | 0.002 | 1.8 – 16.9 |
| Concerns about loss of dignity | 18.1 | 0.007 | 2.2 – 146.5 |
| Average number of concerns | 1.8 | 0.000 | 1.3 – 2.6 |
| Multivariate analysis□ | | | |
| Concerns about dyspnea/suffocation | 4.2 | 0.016 | 1.9 – 13.9 |
| Concerns about loss of dignity | 15.9 | 0.012 | 1.6 – 137.1 |

* Univariate analysis on all relevant variables described and also included variables on illness & treatment history, communication & information at the moment of inclusion and shortly before death, physician's demographic variables, practice & attitude towards euthanasia and palliative care

†Not described in this paper.

□Significant variables have been tested in multivariate analysis using one block for variables at the time of inclusion and one block for variables shortly before death. Finally significant variables were tested in one block (method enter), removing step-by-step variables that did not remain significant.

*Physicians' Reasons for Granting or Refusing a Request*

Table 4 shows the prevalence of requests that were granted, the reasons why physicians grant or refuse a request, the influence on the patient's quality of life, and the physicians' opinion about the decision. Requests to forgo treatment were more often granted than requests to hasten death. Treatment was most often forgone because all treatment options would have been meaningless. Reasons for granting a request to hasten death encompassed a wider range of motive. Differences between granted and not granted requests to forgo treatment and to hasten death were investigated (data not shown). No significant differences were found in the gender and age of the patients or the medical specialty of the attending physician in requests that were granted and not granted. However, the average total number of symptoms was higher in requests to forgo treatment and to hasten death that were granted than in requests that were not granted. Differences in the total number of severe symptoms and severe psychosocial symptoms were significantly higher ($P < 0.05$) in requests to forgo treatment that were granted than in such requests that were not granted. The same pattern of differences appeared among requests to hasten death that were granted and those that were not granted, but these differences were not statistically significant.

*Physicians' Opinions*

The physicians estimated that when the request to forgo potentially life-prolonging treatment was granted, the life of the patient had been shortened by a period of 1–4 weeks in 1/16 cases, by a period of less than 1 week in 2/16 cases, by a period of less than 1 day in 1/16 cases, and that there was no life-shortening effect in 8/16 cases. In 4/16 cases, they did not respond to this question. With regard to the requests to hasten death physicians estimated that granting the request resulted in a life-shortening effect of a period of 1–6 months in 1/4 cases, by a period of 1–4 weeks in 2/4 cases, and by a period of less than 1 day in 1/4 cases (data not shown).

The physicians considered that in the majority of cases the influence of their end-of-life decision on the patients' quality of life was small. Requests to hasten death that were granted led more often to some amelioration of the patients' quality of life (3/4) than requests to forgo treatment that were granted (1/16). The majority of

physicians were satisfied about their decisions with regard to forgo treatment. With regard to their decisions to hasten death, their opinions appeared to differ, and were characterized not only by feelings of satisfaction and relief, but also by a feeling of burdensome responsibility.

**Discussion**

This study investigates the requests concerning end-of-life decisions in terminally ill cancer patients and focuses on describing the background and the evolution of requests related to forgoing treatment and hastening death. There are several important findings. Making a request was related to an increase in the average number of (severe) symptoms and concerns. This was especially the case for requests to hasten death. These requests were also generally based on more reasons than requests to forgo treatment.

Physical and psychosocial symptoms have often been related to requests for hastening death.[12,13,16,17,27-30] In the present study, a high prevalence of fatigue, dependency, and feeling unwell was also found in patients who had made a request to hasten death. By comparing requests to hasten death with requests to forgo treatment, as well as the absence of such requests, it was observed that the clinical course between the moment of inclusion and shortly before death differed between these groups. In patients who made a request to hasten death shortly before death, the average number of symptoms at the moment of inclusion was significantly lower than shortly before death, compared to the other patients. The development of symptoms between the two points in time appeared to be less drastic in patients who made a request to forgo treatment and in patients who had made no request. Thus, the deterioration of the situation might be an important parameter in end-of-life requests. Furthermore, the high number of concerns in patients who had made a request to hasten death might indicate that they see the severity of their situation as threatening. Their choice to hasten death is then not only related to a feeling of hopeless suffering in their current situation, but also to uncertainty about their future. Finally, it was found that loss of dignity, which probably reveals how patients are affected by the severity of the situation, appeared to have a key position in requests to hasten death.

Several studies have described that requests for hastening death are related to psychological suffering.[18,22]

By contrasting requests for hastening death, requests to forgo treatments, and the situation of patients without requests, the influence of psychological suffering appeared even more clearly on patients' desires. Psychosocial problems, e.g., a 'sense of hopelessness' or 'feeling depressed,' have frequently been described as related to requests for euthanasia.[18, 30, 31] Among these problems, hopelessness has been described as having a prominent influence on the desire for hastened death.[32]

The results of the present study also underline the importance of preserving dignity in the patient's life and indicate that (concern about) loss of dignity is tightly related to a feeling of hopeless suffering. Preserving one's dignity appears to be very important for patients and largely contribute to requests for hastening death. Only a few studies have addressed the subject of (loss of) dignity in terminally ill patients.[31,33] Patients with intact dignity have been described as less likely to have a desire for death, as well as to feel less depressed, less anxious, and less hopeless. A fractured sense of dignity together with feelings of depression and of hopelessness has appeared to undermine a patient's desire to continue living in the face of their approaching death.[33]

Most requests to forgo treatment were granted, which indicates that forgoing potentially life-prolonging treatment is becoming 'standard practice,' as has been described elsewhere.[34,35] However, inattentiveness to patients' wishes when deciding about life-sustaining treatments has also been described.[36,37] The presence of severe symptoms was paramount in the physicians' decision to grant a patient's request. It confirms, as has been found in other populations,[38,39] that physicians try to assess patients' unbearable suffering, in particular on the basis of medical aspects.

Most requests to hasten death were not granted. This might be explained by the fact that decisions about requests to hasten death are not associated with normal medical practice because they lead to a more drastic life-shortening effect than by forgoing treatment, are considered to be far-reaching, and have to be reported to the authorities. Moreover, in many cases the patient died before the physician could make a decision.

This study has several limitations. The lack of patient perspective is one of them. The data have been provided by physicians who were asked to complete a monthly questionnaire. The questionnaire mainly consisted of questions used previously in end-of-life

research.[9,10] Furthermore, the limited number of participants in the study threatens the external validity of this study. However, they are retrieved from a representative sample of physicians. The low-inclusion rate could be related to a very optimistic prediction of physicians about the survival period[40] and the limitation that physicians had to treat a cancer patient at the time of the interview. However, the inclusion rate for at least general practitioners and nursing home physicians seems in line with data about the number of terminally ill cancer patients being attended to yearly by these medical specialists in The Netherlands.[41] Finally, because there were no differences found between the physicians who did and did not participate in the follow-up, the inclusion does not seem to be biased in this respect.

Optimal end-of-life care is a complex task, requiring an integrated approach to address patient symptoms.[23,27,30,33-45] Irrespective of the limitations of the study, we believe that the results, by describing how requests concerning end-of-life decisions in terminally ill cancer patients develop, can contribute to improvement of end-of-life care. The originality of the results rely on comparisons between patients' end-of-life requests and a clear description of how the severity and the deterioration of the clinical situation of patients lead to a request by which life could be (in)directly shortened. Physical suffering appears to lead to less drastic requests than suffering blended by concerns and psychological problems. Physicians caring for patients at the end-of-life, therefore, need expertise not only in controlling patients' physical symptoms and preventing rapid deterioration but also in addressing patients' psychosocial problems and concerns, their search for meaning, and in preserving their dignity. By describing terminally ill patients' points of view, more insight would be gained into the background of their requests and their experience of suffering.

| Table 4 Decisions and opinions of physicians related to the different end-of-life requests | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Request | for terminal sedation | | to forgo treatment | | to hasten death | | Total | |
| | n | (%) | n | (%) | n | (%) | n | (%) |
| Decision about the request | n=7 | | n=20* | | n=16 | | n=43 | |
| Granted | 6 | (86) | 16 | (80) | 4 | (25) | 26 | (60) |
| Refused | 1 | (14) | 4 | (20) | 12 | (75) | 17 | (40) |
| Reasons to grant the request | n=6 | | n=16 | | n=4 | | n=26 | |
| Further treatment meaningless | 5 | (83) | 9 | (45) | 3 | (75) | 17 | (65) |
| Suffering was hopeless | 5 | (83) | 7 | (35) | 3 | (75) | 15 | (58) |
| No expectation of recovery | 3 | (50) | 6 | (30) | 3 | (75) | 12 | (46) |
| Quality of life was low | 4 | (66) | 5 | (25) | 3 | (75) | 12 | (46) |
| Suffering was unbearable | 3 | (50) | 1 | (5) | 3 | (75) | 7 | (27) |
| Reasons to refuse request | n=1 | | n=4 | | n=12 | | n=17 | |
| Patient died before decision | 1 | | 4 | (100) | 10 | (83) | 15 | (88) |
| Request not well-considered | - | | 0 | - | 1 | (8) | 1 | (6) |
| Objection in specific case/ never grant | - | | 0 | - | 2 | (16) | 2 | (12) |
| Influence of relatives on request | - | | 0 | - | 1 | (8) | 1 | (6) |
| Treatment options available | - | | 0 | - | 1 | (8) | 1 | (6) |

Table 4 Decisions and opinions of physicians related to the different end-of-life requests

| Request | for terminal sedation | | to forgo treatment | | to hasten death | | Total | |
|---|---|---|---|---|---|---|---|---|
| Influence of decision on patient's QOL(request granted / refused) | Granted | Refused | Granted | Refused | Granted | Refused | | |
| | n=6 | n=1 | n=16† | n=4 | n=4 | n=12† | n=43 | |
| QOL improved very much | 1 | 1 | 1 | | 3 | 3 | 9 | (24) |
| QOL improved somewhat | 4 | - | 5 | 1 | 1 | 2 | 13 | (35) |
| QOL improved barely or not at all | 1 | - | 4 | 2 | - | 3 | 10 | (27) |
| Do not know | - | - | 2 | 1 | - | 2 | 5 | (14) |
| Physician's opinion | | | † | | | | | |
| Satisfaction | 4 | † | 12 | 2 | 2 | 5 | 25 | (58) |
| Feelings of relief | 2 | | 0 | - | 1 | 1 | 4 | (9) |
| Burdensome responsibility | 1 | | 0 | - | 4 | 4 | 9 | (21) |
| Other | - | | | 1 | - | 3 | 4 | (9) |

1 missing case, †Varying number (2 to 5) of missing answers.
More than one answer possible

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*Chapter 4*

# *Differences between terminally ill cancer patients who died after euthanasia had been performed and terminally ill cancer patients who did not request euthanasia*

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**Abstract**

*Goals*

Palliative care, directed at improving the quality of life of terminally ill patients, is generally not aimed at any form of postponing or hastening death. It is possible that high quality palliative care could prevent requests for euthanasia. However, empirical evidence on this issue is scarce. In a national survey of end-of-life medical decisions in the Netherlands the subject of care at the end of life has been addressed.

*Patients and methods*

Data on terminally ill cancer patients who died after their request was granted and euthanasia had been performed were compared with those of terminally ill cancer patients who did not request euthanasia

*Results*

The results show that the prevalence and severity of symptoms e.g. pain, feeling unwell, nausea, was higher in patients who died after their request was granted and euthanasia had been performed. No differences concerning the treatment of symptoms or the care provided were found between the two groups.

*Conclusion*

The results suggest that the practice of euthanasia is mainly related to the patient's suffering.

## Introduction

Palliative care, directed at improving the quality of life of patients suffering from a terminal illness, essentially through prevention and relief of pain and other distressing symptoms, is neither intended to hasten nor to postpone death.[1,2] The relationship between euthanasia and palliative care is subject to debate. One frequently expressed opinion, is that with good palliative care requests for euthanasia and assisted suicide (EAS) can be prevented, and therefore it should never be necessary to perform EAS.[3-5] However, the wish to die and requests for EAS do occur in terminally ill patients,[6,7] and are also reported in terminally ill patients who are receiving palliative care.[8,9] Multiple factors contribute to the development of a patient's request for euthanasia. Many questions are asked about whether and how euthanasia contributes to the quality of the end-of-life, and also about ways in which requests for euthanasia could be prevented or altered by the provision of high quality care. However, empirical evidence is scarce, and the available reports are mainly based on case descriptions.[10]

In order to obtain reliable overviews of euthanasia, physician-assisted suicide and other medical decisions at the end-of-life, quantitative studies of the prevalence and major characteristics of these practices have been carried out in the Netherlands since 1990.[7,11,12]

In the most recent study, specific attention was paid to the care that was provided at the end-of-life and its relationship with EAS.[12]

This paper focuses on possible determinants of EAS, presenting data on symptoms and their treatment, and end-of-life care in two groups of patients, i.e. terminally ill cancer patients whose requests had been granted and euthanasia had been performed, and terminally ill cancer patients who did not request euthanasia.

## Methods

*Design*

In the third study on end-of-life decision-making practices and attitudes in the Netherlands, random samples of physicians, stratified according to specialty, were interviewed about end-of-life decision-making. The interview was the starting point for a prospective study on end-of-life care and its relationship with end-of-life decisions concerning euthanasia. During the interviews incurable cancer patients with a life-expectancy of less than three months and more than one week were included, and subsequently monitored by means of monthly

questionnaires filled in by the physician until the patient's death. The final questionnaire was completed shortly after the patient's death.

The study design ensured absolute anonymity for all participants. Further details about the methods used in the study have been described elsewhere.[12, 13]

*Population*

The specialists included in this part of the study were general practitioners, nursing home physicians, surgeons, internists, pulmonologists, and neurologists. Samples were randomly taken per stratum from the database of the professional registries. Of the 434 physicians in the sample, 87% agreed to be interviewed (n= 376: 174 medical specialists, 125 general practitioners, 77 nursing home physicians). Of the 376 physicians who participated in the study, at the moment of the interview, 120 were treating a patient who met the criteria for inclusion in the prospective study. These criteria were: a diagnosis of cancer, treatment no longer directed at cure, life-expectancy probably no longer than 3 months but longer than 1 week, and probably treated by the respondent until death.

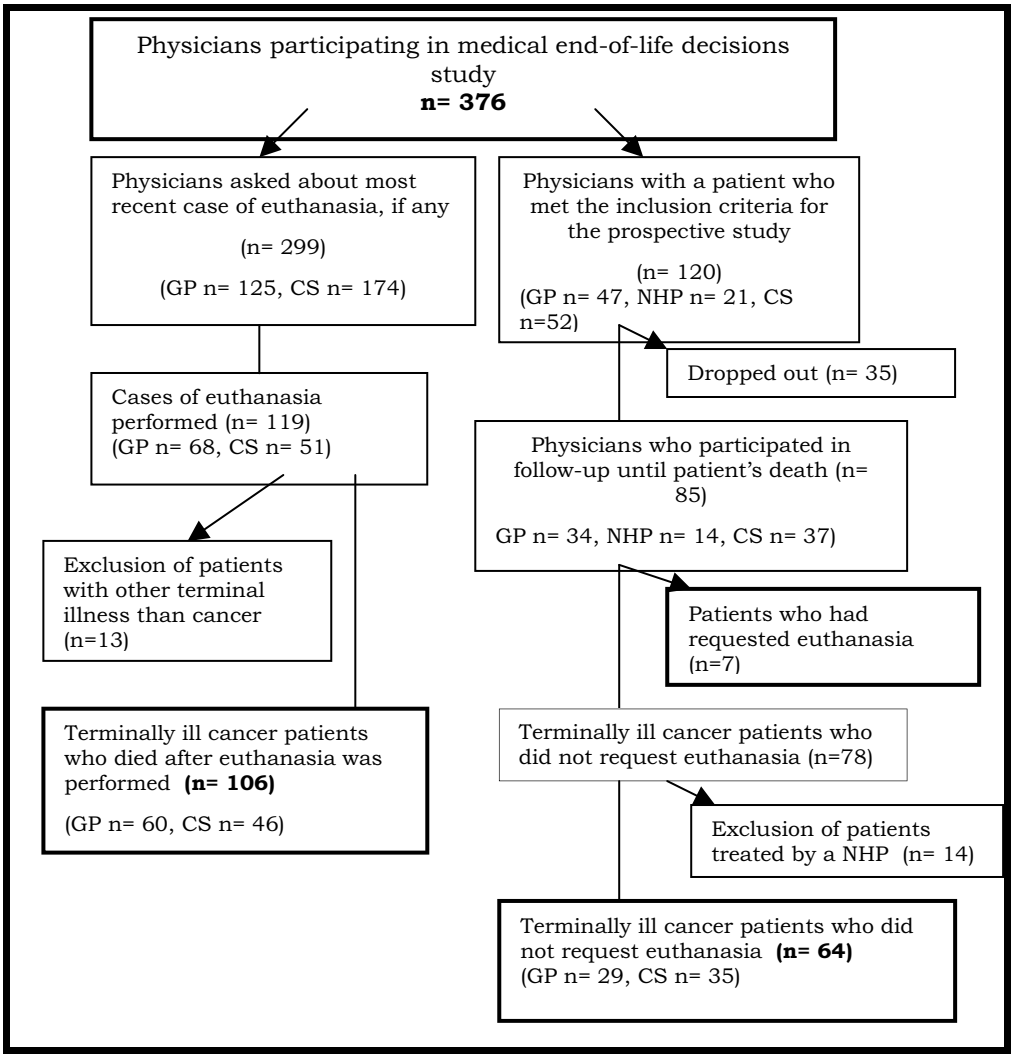
Thirty-five physicians were unwilling to participate or dropped out during the follow-up period, for 85 of these 120 patients the follow-up was completed until their death. Only 7 of these patients had requested euthanasia. This limited number made it impossible to compare patients who did and did not request euthanasia within the prospective study. For this purpose use was made of the retrospective descriptions that the interviewed physicians gave of their most recent case of euthanasia (if any). Of the interviewed physicians, 119 were able to describe a case of euthanasia. In order to make the group as comparable as possible to the group of 78 patients in the prospective study who had not requested euthanasia, we selected only the most recent cases of euthanasia that had been performed for a patient with cancer. We also omitted the cases described by nursing home physicians in the prospective study because they had not been asked to describe their most recent case of euthanasia. This resulted in a comparison between 106 euthanasia cases (that occurred between 1996 and 2002; median 2001) and 64 cases in which the patient did not request euthanasia (study period: 2001-2003). Figure 1 shows this process of selection.

*Measurement instruments*

Experienced physicians, who had been extensively trained to use the structured questionnaires, carried out the interviews. The interviews focussed on experiences and attitudes with regard to end-of-life decision-making. The physicians were asked to describe their most recent cases in which various end-of-life decisions had been made, including euthanasia. Euthanasia was defined as the administration of drugs with the explicit intention of ending the patient's life at his or her explicit request. Physicians who were able to include a patient in the prospective study were interviewed about the patient's current situation and were asked, at the end of the interview, to participate in the study by completing a short questionnaire each month until the patient's death. The questionnaire and the interview schedule, were developed specifically for this part of the study, and reviewed by three physicians with expertise in research on terminally ill patients. The questionnaire included similar questions to those that were asked during the interview, and was designed in such a way that it would not take more than 15 minutes to complete. The questions mainly concerned the patient's medical situation, the patient's symptoms at the time of the physician's last visit, the aim of the treatment, (para-) medical disciplines involved in the treatment, and possible wishes of the patient concerning end-of-life decisions. The final questionnaire had to be completed shortly after the death of the patient. This questionnaire also contained questions about the physician's opinion of the (in)adequacy of care in several domains.

Data concerning the first group, e.g. terminally ill cancer patients who did not request euthanasia before they died, refer to the situation of the patients on the last occasion the physician had visited them before they died. This period had a median length of 1 day (0-47). The data concerning the second group, e.g. terminally ill cancer patients who died after euthanasia had been performed, refer to the moment when the physician decided to grant the patient's request (number of days before death unknown).

**Figure 1 Selection of cases**




GP: general practitioner, NHP: nursing home physician, CS: clinical specialist

*Analysis*

Descriptive statistical analysis was performed on the characteristics of the physicians, the patients, and the patients' symptoms. Symptoms were assessed on a 5-point scale (1= absence of symptoms to 5= presence of symptoms with maximum severity). The respondents were instructed to assess the severity of the symptoms, despite possible treatment of these symptoms. Scores of 2 and 3 were defined as moderate and scores of 4 and 5 as severe. Independent sample t-tests were performed in order to assess the differences in the number of symptoms between the two groups. Wilcoxon signed ranks tests were used to asses the differences in age of the physicians and the differences in age of the patients, Mann-Withney tests to assess differences in characteristics of physicians and differences in the diagnosis of patients and Kruskal-Wallis tests to assess the differences in the prevalence of symptoms. Because physicians could have described only a case of euthanasia or only a case in which the patient had not requested euthanasia, or both situations, these 3 groups were compared to identify possible differences in physician characteristics.

**Results**

Physician characteristics

Table 1 describes the characteristics of the physicians who participated to the study. The various cases included in this study were described by a total of 144 physicians, 70 of whom only described a case of euthanasia, 28 only described a case in which the patient had not requested euthanasia, and 36 described both situations.

Physicians who described the situation of a patient who did not request euthanasia were more often clinical specialists and were younger. Furthermore, they appeared to believe more in the probable influence of palliative care on euthanasia (requests).

| Table 1 Characteristics of physicians | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | Physicians of patients who died after euthanasia (n=70) | | Physicians of patients who did not request euthanasia (n=28) | | Physicians who described both situations (n=36) | |
| | | n | (%) | n | (%) | n | (%) |
| Specialty* | General practitioner | 41 | (59) | 10 | (36) | 19 | (53) |
| | Clinical specialist | 29 | (41) | 18 | (64) | 17 | (47) |
| Age | 25-40 years | 4 | (6) | 6 | (21) | 2 | (6) |
| | 41-50 years | 33 | (49) | 11 | (39) | 20 | (57) |
| | 51-60 years | 26 | (39) | 10 | (36) | 13 | (37) |
| | 61-70 years | 4 | (6) | 1 | (4) | 0 | |
| Gender | Male | 63 | (90) | 21 | (75) | 27 | (75) |
| | Female | 7 | (10) | 7 | (25) | 9 | (25) |
| Have a religious belief | | 23 | (35) | 11 | (39) | 11 | (31) |
| Experience with euthanasia | | | | | | | |
| Have ever had explicit requests for euthanasia or PAS | | 61 | (87) | 23 | (82) | 30 | (83) |
| Have ever performed euthanasia / PAS | | 43 | (70) | 16 | (70) | 22 | (73) |
| Opinion about end-of-life care (Totally) agree with the following statements: | | | | | | | |
| -In the Netherlands much attention has been paid to the regulation of euthanasia and to little to other possibilities to reduce suffering at the end-of-life | | 23 | (33) | 14 | (50) | 14 | (39) |
| -By adequate treatment of pain and adequate end-of-life care euthanasia is made unnecessary* | | 13 | (14) | 13 | (46) | 5 | (14) |
| -The quality of palliative care in the Netherlands is sub-optimal | | 23 | (33) | 11 | (39) | 9 | (25) |
| Development in attitudes during the past 5 years | | | | | | | |
| Became more restrictive | | 16 | (23) | 7 | (25) | 8 | (22) |
| Became less restrictive | | 8 | (12) | 2 | (7) | 1 | (3) |
| No change in attitude | | 45 | (65) | 19 | (69) | 27 | (75) |

[1] PAS: Physician-Assisted Suicide * P< 0.05 (differences between physicians of patients who died after euthanasia and physicians of patients who did not request euthanasia)

Table 2 Characteristics of patients who died after euthanasia and of patients who did not request euthanasia

| | | Patients who died after euthanasia (n=106) | | Patients who did not request euthanasia (n=64) | |
|---|---|---|---|---|---|
| | | n | (%) | n | (%) |
| Age | < 45 years | 18 | (17) | 4 | (6) |
| | 45-60 years | 26 | (25) | 16 | (25) |
| | 61-75 years | 45 | (43) | 32 | (50) |
| | > 75 years | 17 | (16) | 12 | (19) |
| Gender | Male | 58 | (55) | 37 | (58) |
| | Female | 48 | (45) | 27 | (42) |
| Cancer site [1] | Respiratory | 25 | (24) | 19 | (30) |
| | Gastro-intestinal | 33 | (31) | 21 | (33) |
| | Breast | 11 | (10) | 5 | (8) |
| | Gynaecological | 9 | (9) | 3 | (5) |
| | Genitourinary | 11 | (10) | 5 | (8) |
| | Haematological | 6 | (6) | 7 | (11) |
| | Head-neck | 3 | (3) | 2 | (3) |
| | Primary unknown□ | 0 | (0) | 3 | (5) |
| | Other | 6 | (6) | 1 | (1) |

[1] Two patients with two primary sites
□ P< 0.05

*Patient characteristics*

Table 2 describes the characteristics of the patients who died after euthanasia had been performed and of the patients who did not request euthanasia before they died. There were no differences between patients of the two groups with regard to age or gender. The prevalence of the various primary cancer sites was very similar between both groups, with the exception of unknown primary tumor site, which was more prevalent in patients who had requested euthanasia.

*Symptoms*

Table 3 shows the prevalence and means number of severe symptoms in the two study groups.

The prevalence of some symptoms, such as fatigue, feeling unwell and loss of appetite, was noticeably high in both groups.

Patients who died after euthanasia had been performed more often felt unwell, and suffered from severe pain, nausea, vomiting and coughing. They had fewer problems with consciousness and suffered less often from confusion than patients who did not request euthanasia. The prevalence of anxiety and depressive feelings was low in both groups.

The average number of severe physical symptoms was higher in patients who died after euthanasia had been performed, but the average number of psychosocial symptoms was higher in patients who did not request euthanasia before they died.

*Treatment of symptoms and adequacy of care*

Table 4 describes the treatment of certain severe symptoms, e.g. pain, nausea, dyspnoea, depressive feelings and confusion, in the two groups. In both groups the prevalence of treatment of these symptoms appeared to be similar. Physical symptoms, especially pain, were usually treated in both groups. Psychological symptoms, especially depressive feelings, were clearly less often treated than physical symptoms in both groups. With regard to the treatment of confusion, it is difficult to make a reliable comparison between the two groups because of the low prevalence rates.

Table 5 presents data on the adequacy of the care provided. In order to assess whether the care provided was adequate, the physicians were asked if there was any shortage or deficiency in several areas of the care that was needed by the patients. Table 5 shows that in only a few cases in

both groups the physicians estimated that the care provided was inadequate. Differences between the two groups were negligible. When in a certain area the care was described as inadequate, the physicians were asked whether this could have encouraged the patient in some way to make a request for euthanasia. All physicians stated that this was never the case.

Table 3 Prevalence and mean number of severe symptoms in patients who died after euthanasia and patients who did not request euthanasia.

| | Patients who died after euthanasia (n=106) | | Patients who did not request euthanasia (n=64) | |
|---|---|---|---|---|
| | n | (%) | n | (%) |
| Physical symptoms | | | | |
| Feeling unwell□ | 92 | (87) | 46 | (71) |
| Fatigue | 86 | (81) | 52 | (81) |
| Loss of appetite | 80 | (75) | 51 | (80) |
| Pain* | 58 | (55) | 13 | (20) |
| Nausea* | 44 | (42) | 7 | (11) |
| Dyspnoea | 30 | (28) | 17 | (27) |
| Vomiting□ | 27 | (25) | 4 | (6) |
| Coughing□ | 24 | (23) | 5 | (7) |
| Constipation | 21 | (20) | 11 | (17) |
| Pressure ulcer | 3 | (3) | 1 | (2) |
| Number of severe physical symptoms Mean, (SD), [Range]* | 4.4 (1.72) [0-8] | | 3.2 (1.56) [0-8] | |
| Psychosocial symptoms | | | | |
| Anxiety | 17 | (16) | 12 | (19) |
| Depressive feelings | 11 | (10) | 5 | (8) |
| Confusion□ | 2 | (2) | 9 | (14) |
| Unclear consciousness * | 0 | (0) | 21 | (33) |
| Number of severe psychosocial symptoms Mean, (SD), [Range] * | 0.28(0.62) [0-3] | | 0.73 (0.82) [0-3] | |

□ P< 0.05 *P< 0.001

**Discussion**

Patients who died after euthanasia had been performed more often suffered from severe symptoms such as pain, vomiting, nausea and coughing, and more often felt severely unwell. Patients who did not request for euthanasia before they died were more often confused and more often had problems with consciousness. Patients who died after euthanasia had been performed also had a higher average number of severe physical symptoms than patients who did not request euthanasia. However, patients in the latter group had more severe psychosocial symptoms. With regard to the treatment of symptoms, in both groups the symptoms were treated with the same pattern of frequency, and in both groups physical symptoms were more often treated than psychosocial symptoms. With regard to the care that was provided, in the majority of cases the physicians estimated that it was adequate.

Research on palliative care is ethically and methodologically challenging, and this partly explains the paucity of studies that focus on explaining how euthanasia requests could be prevented by providing high quality care.[14-18] The present study is one of the few studies that address issues related to end-of-life care and euthanasia. However, the study design has several limitations that might hamper the possibilities of drawing very firm conclusions. It is important to mention that, although the original design was intended to monitor a group of terminally ill cancer patients and compare within this group the patients who did and did not request euthanasia, this was not possible because only seven patients requested euthanasia. Therefore, we decided to compare the patients who did not request euthanasia with the patients in cases of euthanasia described retrospectively by the responding physicians. This change in approach might have introduced bias. The retrospective design in the euthanasia group could have caused recall bias. However, a request for EAS is an exceptional occurrence, and will therefore be relatively easy to recall.[18] The large majority of respondents described a case of no more than 2 years ago. Moreover, the questions asked in the two groups probably refer to somewhat different points of time in the illness trajectory. The data on patients who died after euthanasia had been performed refer to the period during which the physician was deciding about the request,

Table 4 Treatment of severe symptoms in patients who died after euthanasia and patients who did not request euthanasia

| | Patients died after euthanasia (n=106) | | | Patients who did not request euthanasia (n=64) | | |
|---|---|---|---|---|---|---|
| | Prevalence | Treatment | | Prevalence | Treatment | |
| | n[1] | n | (%) | n[1] | n | (%) |
| Pain | 58 | 58 | (100) | 13 | 13 | (100) |
| Nausea | 44 | 36 | (80) | 7 | 7 | (100) |
| Dyspnoea | 30 | 19 | (63) | 17 | 14 | (82) |
| Depressive feelings | 11 | 3 | (27) | 5 | 1 | (20) |
| Confusion | 2 | 0 | (0) | 9 | 6 | (85) |

1. Number of patients who had the symptom in a severe form.
The percentage is the ratio of patients with the symptom in a severe form who were treated for this symptom

which is generally earlier in the course of the illness than the time of the physician's last visit before the death of the patient who did not request euthanasia. It is therefore probable that the symptoms would have been more severe in patients who died of euthanasia if in this group it had also been possible to use data referring to the time of the physician last visit before the death of the patient.[19,20] Finally, a limitation of this study, regardless of the change in approach, is the fact that the data were provided by the physicians, making it impossible to take the experience of the patients into account. It is possible that the physicians' responses are influenced by the decision they took. It might have been difficult for physicians in both groups to acknowledge inadequacies in care, especially in the domains of care for which they bear the greatest responsibility.

Table 5 Care provided for patients who died after euthanasia and patients who did not request euthanasia

| | Patients who died after euthanasia (n=106) | | Patients who did not request euthanasia (n=30) [1] | |
|---|---|---|---|---|
| | n | (%) | n | (%) |
| Adequate care | 101 | (95) | 27 | (90) |
| Inadequate care | 5 | (5) | 3 | (10) |
| Areas of inadequate care | n | | n | |
| Medical | 0 | | 1 | |
| Nursing | 2 | | 1 | |
| Psychosocial | 1 | | 0 | |
| Spiritual | 1 | | 0 | |
| Domestic, household | 3 | | 0 | |
| Other care facilities | 0 | | 1 | |

1. When patients, apart from not requesting euthanasia, had made no request concerning other end-of-life decisions (e.g. forgoing treatment, terminal sedation) no questions were asked about the adequacy of care

Some interesting results emerged from this study. Compared to physicians who reported the case of a patient who died after euthanasia, physicians who only reported the case of a patient who did not request euthanasia appeared to be more sceptical about the quality of palliative care in the Netherlands and more often believed that euthanasia could be prevented by providing high quality of care. However, physicians' experiences with requests for and the performance of euthanasia are very similar. Therefore it is difficult to really understand in which way the differences in physician characteristics influence the development of a patient's request for euthanasia. It is possible that physicians who only reported the case of a patient who did not request euthanasia provide high quality care, so that their patients request euthanasia less frequently or at a later time in the illness trajectory, or that their patients are hesitant to

request euthanasia because they are aware of the physicians reluctance. In any case, we did not find that anyone group of physicians reported that their patients never made a request for euthanasia.

The fact that inadequate care or lack of attention to the treatment of some symptoms, e.g. pain, nausea, dyspnoea, depressive feelings, confusion, were not more prevalent in either of the two groups, suggests that inadequate care did not contribute to the development of a request for euthanasia in either of the groups. Because of their involvement in the situation, physicians' objectivity could be at stake when assessing the adequacy of the care provided. When judging about the adequacy of care physicians perhaps only refer to the situation of the patient and did not take into account whether other kind of care could have been offered to the patient e.g. specialist palliative care. However, these findings are supported by earlier data,[21] and are in line with results of other studies describing lack of care as a minor reason for patients to request for euthanasia and occurring only in a minority of patients.[8,9,22,23] Conversely, more attention has to be paid to this issue, because unmet care needs have been described as contributing to the likelihood of a patient to consider euthanasia.[15] Only a few studies have focussed on patient needs at the end of life from the perspective of the patients.[24-26]

It was found that there was a higher prevalence of symptoms, such as pain and nausea, and a higher average of severe symptoms in patients who died after euthanasia had been performed than in patients who did not request euthanasia. This could indicate that in the study population (a request for) euthanasia is mainly a result of the patient's suffering. However when interpreting these results we have to keep in mind that unbearable suffering is a prerequisite for euthanasia request to be granted. The burden of pain and physical discomfort has been described in other populations of terminally ill patients as reasons for a request to hasten death,[15,27] and requests for euthanasia are not only made because of physical symptoms. A wide range of reasons seems to contribute to the development of a request for euthanasia. Among these, relationship with others, (concerns about) loss of autonomy, loss of control of bodily functions, concerns about future distress, becoming a burden on others, feeling of meaninglessness, dependency, wish to control the time of

death, or loss of dignity are the most frequently described reasons.[8,22,28]

The results show that in patients who did not request euthanasia the number of psychosocial symptoms was higher than in patients who died after euthanasia had been performed. Considering the fact that psychosocial symptoms e.g anxiety, feeling of hopelessness, have been described as factors contributing to the development of requests for euthanasia, we may be surprised by these results.[29-31] However the high prevalence of problems with consciousness and confusion in patients who did not request euthanasia could explain why, in this group, the number of psychosocial symptoms is more important, as these two symptoms make it less likely, if not impossible, to meet at least one of the requirements for prudent euthanasia practice that exist for euthanasia, namely that the request should be well-considered. Furthermore, the lower prevalence of psychosocial symptoms found in patients who died after euthanasia had been performed is in line with the results of studies on physicians' decisions about requests for euthanasia, in which it was found that patients whose requests were not granted had more mental health problems, and especially depression, than patients who died after euthanasia had been performed.[27,32]

The results indicate that physical symptoms were more often treated than psychosocial symptoms, which has also been observed in other populations of terminally ill patients.[31] It is worth noting that, not only the prevalence of depressive feelings, but also the frequency of treatment for depressive feelings was similar in both groups. Depressive feelings did not seem to be an important discriminating factor between the two groups, and there was not clear influence of depressive feelings on the development of requests for euthanasia.

In conclusion, it appears that the number of symptoms and the severity of certain symptoms, such as pain, nausea, coughing and vomiting, clarify why the patients in the study population requested euthanasia. These symptoms seem to make an important contribution to the unbearable suffering that is a requirement for granting a request for euthanasia. No evidence has been found to support the assumption that a lack of care and inadequate treatment of symptoms contribute to the development of requests for euthanasia. Until now, only a few studies have addressed the association between end-of-life care and requests

for euthanasia.[9,15,28] Further studies are needed to investigate the contribution of palliative care in terminally ill patients who wish to hasten death and develop a request for euthanasia. Taking into account the limitations of this study, future efforts should concentrate on describing the illness experience of terminally ill patients in order to gain insight into the meaning of their request for euthanasia. Furthermore, more specific attention should be paid to comparing terminally ill patients who request euthanasia with terminally ill patients who do not. A prospective study design seems to be the most appropriate for this purpose, among others because attention can also be paid to requests for euthanasia that do not result in euthanasia.[16,33-35]

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# *Chapter 5*

# *Relatives' perspective on the terminally ill patients who died after euthanasia or physician-assisted suicide: A retrospective cross-sectional interview study in the Netherlands*

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*Death Studies (in press)*

**Abstract**

This study used retrospective interviews with 87 relatives to describe the experiences of patients who died by euthanasia or physician-assisted suicide (EAS) in the Netherlands.

Most of the patients suffered from cancer (85%). The relatives were most often a partner (63%) or a child (28%) of the patient.

Before explicitly requesting EAS most patients (79%) had spoken about their wishes concerning medical end-of-life decisions to be made at a later date.

Hopeless suffering, loss of dignity and no prospect of recovery were the most prevalent reasons for explicitly requesting EAS. According to the relative, in 92% of patients EAS had contributed favourably to the quality of the end of life, mainly by preventing or ending suffering.

## Introduction

Euthanasia, defined as the administration of drugs with the explicit intention to end a patient's life at his or her request, and physician-assisted suicide, defined as the prescription or supply of drugs with the explicit intention to enable a patient to end his or her own life, are legal in the Netherlands, provided that the requirements for prudent practice are met.

Several studies have described the experiences and attitudes of physicians with regard to euthanasia and assisted suicide (EAS).[1-4] The relationship between euthanasia and the bereavement of relatives of patients who died after EAS has also been described.[5] However, although the clinical and demographic characteristics of patients requesting euthanasia have been investigated,[6] their experiences and life circumstances have not been studied.[7]

The objectives of the study were to gain insight into the background and history of requests for EAS and into the influence and meaning of EAS on the end of a patient's life. Therefore, in the third nationwide study concerning medical end-of-life decisions in the Netherlands, the relatives of patients who died after EAS were interviewed.[8]

## Methods

Design

During one of the sub-studies of the third nationwide study concerning medical end-of-life decisions in the Netherlands, a random sample of physicians who had reported cases of EAS to the Regional Review Committee (RRC) in the year 2001 (n=2054 cases), stratified according to specialty and the district in which the case was reported, were interviewed. The study design ensured absolute anonymity for all participants.

*Population and procedure*

All 167 physicians who were interviewed (74 general practitioners, 65 medical specialists, 28 nursing home physicians) were asked to approach the patient's most involved relative in order to inform them about the study and to invite them to participate. A member of the research team then contacted the relatives who were willing to participate about the study, and an appointment was made for an interview.

In the case that a relative of the patient could not be approached it was because the relative would not be able to participate in an interview e.g. due to an illness, emotionally too demanding (n=16), the interviewer did

not ask the physician to approach the relative (n=16), or the relative could not be found (n=16). In the remaining cases it was not clear why a relative had not been approached (n=22).

Finally, of the 97 relatives who had been approached, 87 (response rate 90%) agreed to participate; 3 refused because of lack of time, and 7 explained that it could be too emotional to talk about the patient. Relatives were interviewed between October 2001 and January 2002, and the mean period between the death of the patient and the interview with the relative was 17.6 (+/- 4.45) months, (range 6-32).

*Measurements instruments*

The interview schedule mainly focused on the patient's illness, the reasons for the patient's wishes and requests for EAS, the end of the patient's life and the dying process. The interview schedule was specifically developed for this study and pre-tested with 4 relatives of patients who died after EAS some years earlier. The interview questions were formulated in a way that the answers could be written down easily during the interview. The interviews, which had an average length of two hours, were held in the home of the relative, and the interviewers were specifically trained for the purpose of the study.

*Data-analysis*

Descriptive statistical analysis was performed on the characteristics of the patients and their relatives. As earlier studies have shown that the gender and age of the patient are related to the type of end-of-life decisions,[9,10] the reasons for requesting EAS and the concerns of the patients were analysed for sub-groups of the total population, according to gender and age. The median value, 68 years of age, was used as the cut-off point. Sub-group differences concerning the reasons for requests and concerns were assessed by non-parametric tests, and differences concerning the average number of concerns by a t-test. Differences in the results, according to the gender of the relative and his/her relation to the patient, were also assessed.

| Table 1 Characteristics of relatives and patients (n=87) | | | | |
|---|---|---|---|---|
| Relatives | Age | Mean: 58 (± 13.4) | n | % |
| | Gender | Male | 36 | 41 |
| | | Female | 51 | 59 |
| | Relation to patient | Partner | 55 | 63 |
| | | Child | 24 | 28 |
| | | Other relative | 4 | 5 |
| | | Friend | 2 | 2 |
| | | Other | 2 | 2 |
| | Education[1] | Primary school | 20 | 23 |
| | | Secondary school | 36 | 42 |
| | | High school/university | 29 | 33 |
| | | Other | 1 | 1 |
| | Health insurance[1] | Sick fund | 47 | 54 |
| | | Private insurance | 40 | 46 |
| | Religious beliefs[1] | Yes | 40 | 46 |
| Patients | Age | Mean: 66 (±14.1) | | |
| | Gender | Male | 48 | 55 |
| | | Female | 39 | 45 |
| | Diagnosis | Cancer | 73 | 85 |
| | | Other | 14 | 15 |
| | Reason of death | Euthanasia | 84 | 97 |
| | | Physician-assisted suicide | 3 | 3 |
| | Place of death[2] | Home | 45 | 52 |
| | | Hospital | 26 | 30 |
| | | Nursing Home | 14 | 16 |
| | | Hospice | 2 | 2 |

[1] According to the national bureau of statistics in the Netherlands, CBS Voorburg/Heerlen (retrieved on 27-10-2005) these variables are distributed as follow for the Dutch population in the year 2001: with concern to education 25% of the people between 25-64 years old have a higher school or university degree and 30% , same age category have a low level of education (primary school). With concern to health assurance 66% have sick fund and 34% Private insurance and with concern to religious belief 59% have one.

[2] In the Netherlands of all deaths (n=142000, year 2003) about 33% occurred at the hospital, about 25% at home, en about 20% at a nursing home. Of the patients, between 20 and 79 years old, who died of cancer in the year 2003 about 35% died at the hospital, about 50% at home, about 8% at a nursing home and 7% at an other place. CBS, webmagazine, 21 juni 2004. http://www.cbs.nl/nl-nl/menu/themas/dossiers/vergrijzing/publicaties/artikelen/archief/2004/2004-1483-wm.htm

**Results**

*Characteristics of participants*

The relatives participating to the study had a mean age of 58 (+/-13.4) years old, 41% were male, 63% were the partner of the patient (Table 1). For 91% of the relatives it was the first time that they had been closely involved in a request for EAS. The mean age of patients was: 66 (+/-14.1) years old, 55% was male, 85% of them suffered from cancer and 15% of an other illness, mostly a neurological disease (e.g. amyotrophic lateral sclerosis, spinal cord injury). Almost all of the patients (97%) died after euthanasia, but 3% died after physician-assisted suicide. Slightly more than half of the patients died at home (52%), 30% died in a hospital, 16% died in a nursing home, and 2% died in a hospice. In 48% of the cases the attending physician was a general practitioner, in 36% a clinical specialist, and in 16% a nursing home physician.

*Talking about medical end-of-life decisions at a later date*

Most patients (79%) had expressed their wish concerning medical end-of-life decisions before they became terminally ill (median 1 year before death, range 1 week – 20 years). The wishes almost always concerned euthanasia (84%), had mostly been expressed in writing (59%) and were mainly directed at circumstances of unbearable suffering and heavy dependence on others to perform daily life activities (67%). Most of the patients had first talked to their partner (69%) or one of their children (38%) about considering EAS as an option at a later date. In a minority of cases the physician was involved (39%) (Table 2).

*Requesting euthanasia or assisted suicide explicitly*

Most explicit requests for EAS were made within 3 months of the patient's death (Table 3). A minority of patients (10%) found it difficult to explicitly request a physician to perform EAS. According to their relatives, most patients (74%) were satisfied about the way in which the physician handled their request because they felt that the physician had insight. However, 16% of the patients were disappointed, and 10% were undecided because of the physician's ambivalent attitude to their request.

| Table 2 Circumstances of talking about euthanasia or physician assisted suicide (EAS) at a later date (n=87) | | | |
|---|---|---|---|
| | | n | % |
| Patients who had expressed a wish concerning medical end-of-life decisions before becoming terminally ill | | 69 | 79 |
| | | | |
| Way the wishes were expressed | In writing | 41 | 59 |
| | Only verbally | 28 | 41 |
| Object of the wishes* | EAS | 58 | 84 |
| | Other medical end-of-life decisions | 10 | 15 |
| Circumstances the wishes focused on [1] | | | |
| | Unbearable and/or meaningless suffering | 31 | 45 |
| | Heavily dependent for daily life activities | 15 | 22 |
| | Life without dignity | 6 | 9 |
| | Other or not specified | 20 | 29 |
| Persons to whom patients talk the first time about considering EAS:[1] | | 87 | |
| | Partner | 60 | 69 |
| | Children | 32 | 38 |
| | Other relatives | 11 | 13 |
| | Physicians | 33 | 39 |
| | Other | 6 | 7 |

* 1 missing value

[1] More than one answer possible

| Table 3 Circumstances of the first explicit request (n=87) | | |
|---|---|---|
| | n | % |
| Time of first explicit request | | |
| < 1 week before death | 25 | 29 |
| 1 week – 1 month before death | 28 | 33 |
| 1 month – 3 months before death | 19 | 22 |
| 3 months – 1 year before death | 11 | 13 |
| > 1 year before death | 3 | 3 |
| Experience of making the request | | |
| Did not find it difficult to make request to the physician | 78 | 90 |
| Found it difficult to make request to the physician | 9 | 10 |
| Experience of physician's reaction | | |
| Satisfied with physician's reaction to the request | 64 | 74 |
| Disappointed about physician's reaction to the request | 14 | 16 |
| Neutral about of physician's reaction | 9 | 10 |

Table 4 presents patients' concerns and patients' reasons for requesting EAS. The most widely expressed concerns were about loss of dignity (60%), ADL-dependency (47%), and pain (42%). Women were more often concerned about pain than men (z=-2.229; p= 0.026), about confusion (z=-2.080; p= 0.038) and about the dying process (z= -1,954; p= 0.051). Patients under 68 years of age were more concerned about missing an important event (e.g the wedding of a child or the birth of a grand-child) (z= -2.125; p= 0.034), while patients over 68 years of age were more concerned about admission to a hospital (z= -2.655; p= 0.008).

The partners more often than the children reported that the patient was concerned about missing an important event (z= -2.156; p= 0.031).

The patients had a mean of 4 (SD +/-2.2) concerns, but men (mean 3.44, SD +/-1.7) had significantly fewer concerns than women (mean 4.77, SD +/-2.46) (t= -2,919; p= 0.004).

No differences were found with regard to age. Hopeless suffering, loss of dignity and no prospect of recovery were the most frequently mentioned, and also the most important reasons for requesting EAS.

Men more often than women requested EAS because of fear of suffocation (z= -1.957; p= 0.043). This was not related to suffering from cancer of the respiratory tract, which was more prevalent in men. Women more frequently than men requested EAS because they wanted to be able to say good-bye to their loved ones consciously (z= -2.259; p= 0.037). There were no differences with regard to age.

Partners more often than children reported that meaningless suffering was a reason for the patient to request EAS (z= -1.953; p= 0.051), and female proxies more often than male proxies reported fear of suffocation (z= -2,202; p= 0.028).

*EAS, the end of life and the dying process*

Relatives reported that EAS had clearly contributed to the quality of the end of life of the patient (92%), that EAS had contributed to some degree to the quality of the end of life of the patient (7%), and one relative could not judge. Relatives who made some comments (n= 49) emphasized that EAS contributed to the quality of the end of the patient's life because by shortening life further suffering could be avoided (37%), because the patient knew that his/her wish concerning the end of life would be respected (29%), because dignity in dying would be preserved

(18%), and because unbearable suffering would be alleviated (16%). Death had occurred at the right time according to most relatives (77%). However, some of them considered that EAS had been performed too late in the course of the patient's illness, therefore causing more pain and suffering (23%). According to relatives, all the patients were ready to die (100%), most of them had said good-bye before dying (97%) and had died peacefully (93%).

**Discussion**

The results of this cross-sectional study indicate that the majority of patients who died after EAS had expressed a wish concerning medical end-of-life decisions before they became terminally ill. According to their surviving relatives, patients were, above all, concerned about loss of dignity, ADL-dependency, pain and being a burden. Loss of dignity and hopeless suffering were the most important reasons for requesting EAS. According to the relatives, all the patients were ready to die, and almost all the patients had said good-bye to their loved ones and had died peacefully. EAS mainly contributed to the quality of the end of the patient's life by preventing or ending their suffering.

Earlier studies have described the importance of relatives in relation to medical end-of-life decisions.[11, 12] Most patients first talked about their wishes concerning the end of life with a relative, which indicates the intimate character of this issue, and only later with their physician. However, because physicians in the Netherlands need to take time to meet the requirements of prudent practice before granting a request and to cope with the patient's request,[4,13,14] it is important that both the physician and the patient get insight in the point of view of each other earlier on in the illness process.

The data show that the patients' explicit request for EAS generally developed over a longer period, first talking to close relatives about their wishes concerning medical end-of-life decisions and describing circumstances with which they would not like to be confronted. This mostly happened before their illness had progressed to the terminal stage. Requesting EAS explicitly generally occurred relatively late in the illness process.

Table 4 Patients' concerns and reasons for explicitly requesting EAS according to gender and age

| | Patient's gender | | | | Patient's age | | | | Total | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Male n=48 | Female n=39 | | | ≤ 68 n=45 | > 68 n=42 | | | n=87 | |
| **Concerns** | % | % | Z | P* | % | % | Z | P* | n | % |
| Loss of dignity | 54 | 67 | -1.176 | 0.240 | 60 | 60 | -0.045 | 0.964 | 52 | 60 |
| ADL-dependency | 46 | 49 | -0.267 | 0.790 | 49 | 45 | -0.339 | 0.735 | 41 | 47 |
| Pain | 31 | 54 | -2.229 | 0.026 | 47 | 37 | -0.941 | 0.347 | 36 | 42 |
| Being a burden on others | 33 | 49 | -1.447 | 0.148 | 40 | 41 | -0.045 | 0.964 | 35 | 40 |
| Admission to hospital | 40 | 41 | -0.136 | 0.892 | 27 | 55 | -2.655 | 0.008 | 35 | 40 |
| No longer able to communicate | 23 | 41 | -1.805 | 0.071 | 33 | 29 | -0.477 | 0.633 | 27 | 31 |
| Dyspnoea | 27 | 26 | -0.151 | 0.880 | 18 | 36 | -1.885 | 0.059 | 23 | 26 |
| Dependent on medical technology | 19 | 28 | -1.036 | 0.300 | 19 | 29 | -1.189 | 0.235 | 20 | 23 |
| Confusion | 13 | 31 | -2.080 | 0.038 | 27 | 14 | -1.416 | 0.157 | 18 | 21 |
| Missing important event | 13 | 13 | -0.044 | 0.965 | 20 | 5 | -2.125 | 0.034 | 11 | 13 |
| Loneliness | 10 | 10 | -0.024 | 0.981 | 4 | 17 | -1.860 | 0.063 | 9 | 10 |
| Not fully conscious | 4 | 13 | -1.467 | 0.142 | 9 | 7 | -0.297 | 0.766 | 7 | 8 |
| Addiction medication | 4 | 10 | -1.108 | 0.268 | 4 | 10 | -0.929 | 0.353 | 6 | 7 |
| Fear the dying process | 2 | 13 | -1.954 | 0.051 | 9 | 5 | -0.755 | 0.450 | 6 | 7 |
| Fear of death | 2 | 7 | -1.235 | 0.217 | 7 | 2 | -0.948 | 0.343 | 4 | 5 |
| Others | 8 | 11 | -0.346 | 0.730 | 9 | 10 | -0.137 | 0.891 | 8 | 9 |

Table 4 Patients' concerns and reasons for explicitly requesting EAS according to gender and age

| **Reasons*** | % | % | Z | P* | % | % | Z | P* | n | % |
|---|---|---|---|---|---|---|---|---|---|---|
| Hopeless suffering | 71 | 77 | -0.637 | 0.524 | 71 | 76 | -0.534 | 0.594 | 64 | 74 |
| Loss of dignity | 58 | 54 | -0.417 | 0.677 | 60 | 52 | -0.712 | 0.477 | 49 | 56 |
| No prospect of recovery | 46 | 39 | -0.688 | 0.492 | 38 | 48 | -0.922 | 0.356 | 37 | 43 |
| Meaningless suffering | 44 | 26 | -1.744 | 0.081 | 36 | 36 | -0.015 | 0.988 | 31 | 36 |
| ADL-dependency | 33 | 36 | -0.249 | 0.804 | 31 | 38 | -0.681 | 0.496 | 30 | 35 |
| General weakness | 40 | 26 | -1.364 | 0.173 | 36 | 31 | -0.453 | 0.651 | 29 | 33 |
| Pain | 25 | 41 | -1.582 | 0.114 | 38 | 26 | -1.149 | 0.250 | 28 | 32 |
| Not being a burden on others | 15 | 31 | -1.807 | 0.071 | 22 | 21 | -0.089 | 0.929 | 19 | 22 |
| Fear of suffocation | 27 | 10 | -1.957 | 0.043 | 18 | 22 | -0.427 | 0.670 | 17 | 20 |
| Immobility/invalidity | 17 | 21 | -0.458 | 0.647 | 22 | 14 | -0.949 | 0.342 | 16 | 18 |
| Vomiting | 10 | 13 | -0.348 | 0.728 | 11 | 12 | -0.115 | 0.908 | 10 | 12 |
| Tired of life | 10 | 5 | -0.897 | 0.370 | 7 | 10 | -0.487 | 0.626 | 7 | 8 |
| Depression | 6 | 3 | -0.812 | 0.417 | 4 | 5 | -0.070 | 0.944 | 4 | 5 |
| Saying good-bye consciously | 0 | 10 | -2.259 | 0.037 | 7 | 2 | -0.948 | 0.343 | 4 | 5 |
| Other symptoms e.g. nausea | 2 | 5 | -0.770 | 0.442 | 2 | 5 | -0.645 | 0.519 | 3 | 3 |
| Others | 6 | 5 | -0.222 | 0.824 | 9 | 2 | -1.296 | 0.195 | 5 | 6 |

| **Most important reasons[1]** | Male n=48 | Female n=39 | | | ≤ 68 n=45 | > 68 n=42 | | | n=87 | |
|---|---|---|---|---|---|---|---|---|---|---|
| | % | % | Z | P* | % | % | Z | P* | n | % |
| Loss of dignity | 33 | 32 | | | 32 | 33 | | | 28 | 32 |
| Hopeless suffering | 19 | 32 | | | 25 | 24 | | | 21 | 24 |
| Meaningless suffering | 15 | 3 | | | 7 | 12 | | | 8 | 9 |
| No prospect of recovery | 4 | 11 | | | 7 | 7 | | | 6 | 7 |
| General weakness | 8 | 3 | | | 5 | 7 | | | 5 | 6 |
| | | | | | | | | | | |

* More than 1 answer possible [1] Most important reasons among all reasons described

Even if the request had been considered for a long time, as indicated by the high number of patients who had expressed their wishes concerning EAS in writing for an extended period before death, the patients seemed to strive to carry on as long as possible before requesting EAS explicitly.

It is known that only about one third of queries about EAS at a later time develop into an explicit request for EAS [8] and that requests for EAS are related to advancing disease.[15]

Earlier studies have reported that patients who explicitly request EAS have a more drastic deterioration in their clinical situation and symptoms than patients who made no request.[16,17] Comparing our data with earlier studies among cancer patients dying without EAS suggests that patients who died after EAS had more concerns,[17] and were more frequently ready to die, had more frequently said good-bye to their loved ones and more frequently died peacefully.[18] Loss of dignity was among the most important reasons why patients made a request for EAS and it was their most important concern. It is known that proxy reports on psycho-social problems of patients might be ambiguous,[19] therefore it is difficult to ascertain whether they were purely reporting on patient's experience of dignity and were able to set aside their own view. However, psychosocial problems and factors related to loss of dignity have been described by physicians and by patients as well as an important reason for patients to request euthanasia.[16,20-22] Dignity is a very personal feeling; it is probable that conditions such as being ADL-dependent, being a burden on others, and general weakness threaten a patient's dignity more than previous ideas and expectations about the end of life, and also determine the moment when an explicit request for EAS is made.

According to relatives in our study group, EAS mainly contributes to the quality of the end of the patients' life because their wishes are respected and further suffering is prevented. It also appeared that knowing how one's own wishes and requests for euthanasia will be treated generated feelings of trust and control, thus possibly contributing favorably to the quality of the end of the patient's life.

*Limitations*

It is a limitation that only cases reported to the RRC were included in the study sample. However, differences with regard to patient characteristics between reported and unreported cases of EAS in the Netherlands are mainly

related to procedural requirements for prudent practice (e.g. consultation of another doctor before proceeding) and not with substantive requirements (e.g. the unbearable and hopeless condition of the patient).[23]

The reliability of the data could be affected by the retrospective study design and by the fact that proxies were the only available source of data. However the strength and weakness of studies based on proxy reports have largely been clarified.[19,24-26] Furthermore the relatives who participated in the present study were the most closely involved in the patient's situation. However we have to be aware that their answers might be influenced by their personal point of view and experiences (e.g. when judging that euthanasia had contributed to the quality of the patient's end-of-life).

Furthermore, it is a limitation that eligible study participants first had to be approached by the attending physicians, which might have resulted in an overrepresentation of unproblematic cases. However, this could be the case in 38/70 relatives who were not approached because of subjective reasons (e.g. relative was thought to be too emotional, not able to participate or unknown). In other cases (32/70), as the reasons to not approach a relative were more related to the study procedure (e.g. interviewer forgot to ask the physician to approach a relative or the relative could not be found anymore), it is less probable that selection was related to the case being problematic.

The use of structured questions may also have limited the scope of the answers of the participants. However participants were asked regularly during the interview to talk freely or to make any comments related to their experiences or those of the patients.

The results of the present study might be developed further by in future study research including data about a comparison group of terminally patients who did not die after EAS.

Even with these limitations, however, this study contributes useful detail to our understanding of the perceived meaning and impact of requests for hastened death at the end of life.

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# *Chapter 6*

# *Dealing with requests for euthanasia: a qualitative study investigating the experience of general practitioners*

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*(Conditionally accepted)*

## Abstract

*Goals*

Caring for terminally ill patients is a meaningful task, however the patient's suffering can be a considerable burden and cause of frustration.
The aim of this study is to describe the experiences of general practitioners (GPs) in the Netherlands in dealing with a request for euthanasia from a terminally ill patient.

*Methods*

The data, collected through in-depth interviews, were analysed according to the constant comparative method.

*Results*

Having to face a request for euthanasia when attempting to relieve a patient's suffering was described as a very demanding experience that GPs generally would like to avoid. Nearly half of the GPs (14/30) strive to avoid EAS because it was against their own personal values or because it was emotional burdening to be confronted with this issue. They explained that by being directed on promoting a peaceful dying process, or the quality of end-of-life of a patient by caring and supporting the patient and the relatives it was mainly possible to shorten patient's suffering without 'intentionally hastening a patient's death on his request'. The other GPs (16/30) explained that as sometimes the suffering of a patient could not be lessened they were open to consider a patient's request for EAS. They underlined the importance of a careful decision-making process, based on finding a balance between the necessity to shorten the patient's suffering through euthanasia and their personal values.

*Conclusion*

Dealing with requests for euthanasia is very challenging for GPs, although they feel committed to alleviate a patient's suffering and to promote a peaceful death.

**Introduction**

Caring for terminally ill patients has been described as an essential aspect of a GP's experience which can often be very rewarding.[1-3] The continuity of contacts, the long-standing relationship with patients, the fact that the care is embedded in a family and community relationship, working as part of a team to co-ordinate the care, controlling symptoms, providing psychosocial support, communicating honestly with patients and their family, and supporting relatives of the dying, have been described as the most valuable aspects of a GP's experience in caring for the terminally ill.[2,3] Furthermore, feeling satisfied about their own experience of caring for the terminally ill appeared to be closely related to the GP's emotional involvement in the patient's situation.[2]

However, caring for terminally ill patients has also often been described as distressing and frustrating, and as a source of psychiatric morbidity in physicians.[4-6] Difficulties related to symptom control, dealing with the emotional distress of the relatives and attending to the psychosocial needs of the patients have been described as the most frustrating aspects of end-of-life care.[1,3] The GP's long-standing relationship with the patient and intimate involvement in the patient's situation might lead to strong emotional reactions and to emotional distress, particularly when the patient dies.[3, 6, 7] It has also been suggested that this involvement of GPs with the terminally ill could lead to a lack of confidence in their own ability to relieve a patient's symptoms successfully and to difficulties in coping with a patient's request for euthanasia.[3]

Surprisingly, even if dealing with requests for euthanasia or physician-assisted suicide (EAS) is recognised as being a considerable burden, only a limited amount of research has investigated the GP's experience of dealing with a request for EAS from a terminally ill patient who is suffering.[8-10]

GPs are the physicians who are most often confronted with a patient's request for EAS and assisted suicide in the Netherlands.[11] They also are increasingly more often involved in developments and training related to palliative care.

The aim of this study is to describe GP's experiences of dealing with requests for EAS from terminally ill patients.

**Method**

*Participants*

The GPs participating to a nationwide study of end-of-life decision-making practices in the Netherlands[11] were approached in order to ask them whether they would like to participate to a further qualitative interview about their experience with regard to end-of-life care and more explicitly with requests for EAS. Eighty-one (65%) of the 125 GPs who participated at the nationwide study, were willing to participate in the qualitative study. Age, gender, location of general practice were used as criteria to select a sample from these 81 GPs. After 31 interviews it was judged that enough data had been collected in order to describe physicians' experience. Because one of the interview tapes was damaged, only 30 interviews could be used for the purpose of the present study. The characteristics of the physicians who participated in the study are described in Table 1.

*Data-collection procedure*

Data were collected through in-depth interviews between September 2002 and March 2003. Initial questions were aimed at gaining insight into the background of the medical practice of each GP interviewed and their experience with caring for terminally ill patients. The questions were derived from topics of interest related to a GP's opinion about end-of-life care and medical end-of-life decisions, mainly focussing on experiences and attitudes with euthanasia. The topics formed the basis from which the interviewer or the GP could diverge in order to explore an idea in more detail.[12, 13] (Box 1)

All the interviews, which were conducted by the same researcher (AMT) took place in the GP's practice, lasted 1.15 to 2.5 hours, and were tape-recorded.

*Analysis*

The interviews were transcribed verbatim. The analysis took place in accordance with the principles of the constant comparative method, and was aimed at identifying recurrent themes with regard to the GP's approach when dealing with a request for euthanasia.[14-16] The analysis included coding data repeatedly, moving from a concrete to a more abstract level of coding, formulating themes, looking for concrete indicators of the themes, and writing memos. Initially, the analysis was performed 'by hand', but subsequently supported by the use of a Winmax computer programme.[17] The results of the analysis were regularly discussed by the researchers (JJG & AMT) in order to identify

inconsistencies and to determine relevance of the interpretations. Presentation of the findings to other members of the research team (BOP, G vd W) resulted in further clarification and verification of the results.[18-20]

**Results**

The GPs described caring for terminally ill patients as a very important and meaningful part of their function. They considered their task to be mainly concerned with the patient's quality of life, alleviating the patient's suffering and supporting the patient and the relatives. They emphasized the importance of being available when necessary for the patient. They explained that caring for the terminally ill was a very meaningful experience, not only because of their increased role in (co-ordinating) the care, but also because of their particular involvement in the patient's situation.

*I think that you go down an emotional path with the patient. Unfortunately we do not have any more births, that's a pity because I enjoyed that. Then you are very close to people. But when you are with people who are dying, than you are very much closer. Almost closer than when someone is having a baby…(woman 45-55 years old)*

However, GPs described dealing with requests for EAS from terminally ill patients as very demanding and as a heavy responsibility. They frequently talked honestly about the way in which they tried to cope with euthanasia requests and about the emotional consequences of having to perform euthanasia.

*I think people don't really realise what it means for a GP to have to perform euthanasia. They think 'the doctor will come and give the patient an injection, and that's it. They forget everything about what has to happen beforehand, that you have to think about it and that you are emotionally very much involved. The day that you do it you can't do other work. I don't mean this in a negative way, but you can't do anything else. It's drastic. In the past you were also confronted with the coroner, the Public Prosecutor had to be called, and then you had to wait until you were informed whether or not everything was right, and you were finally informed that it would not become a court case. (man 55-65 years old)*

GPs made clear how important it is, whatever they decide about a request for euthanasia, to be sure about their decisions and to might feel at ease

about the way they try to lessen a terminally ill patient suffering.

Their approach of a request for EAS was mainly related on their opinion on EAS and the end-of-life of a patient. Some of them, nearly half of the interviewed GPs, strove to avoid to have to perform euthanasia believing that it could be possible to lessen a patient's suffering in another way e.g. by using morphine or paying attention to the quality of life of a patient. The other GPs, described they were open to consider the request of a terminally ill patient who was suffering. These approaches are described below.

**Considering other ways than EAS to lessen a terminally ill patient suffering**

Some GPs (6/30) stated that they were not in favour of performing euthanasia and explained that they tried to avoid having to perform euthanasia above all because euthanasia was not compatible with their own way of alleviating the suffering of terminally ill patients. Some of them underlined that their attitude against euthanasia was related to their religious beliefs, other GPs underlined being uncertain about their own ability to cope with hastening a patient's death intentionally.

*I can quite well imagine that whenever the body gives up, or when someone is terminally ill, you have to accept that and let the patient die. If there is something that can make the process faster I will never oppose that. If somebody has signs of general fatigue, cancer with complications like a lung infection, etc […] and would have a peaceful death, I wouldn't bother the patient with treatment. I think dying in such a way is part of life. But actually to give someone an injection, and then being confronted with the responsibility… I don't want that. I still find it nasty, I'm against it, just like abortion, I will never do that. If someone else wishes to do it…(woman 45-55 years old)*

These GPs explained that, instead of euthanasia, they preferred to administer large doses of opioids and terminal sedation in order to alleviate the suffering of the terminally ill patient. They stressed that such medical decisions are directed at supporting the (dying) patient but not intentionally hastening the patient's death. Because they often preferred not to interfere directly with the dying process they chose to wait a while before taking a medical end-of-life decision, anticipating that the death

could happen soon without any need for external interference.

*Sometimes I'm working on the borderline, and I know this. When I have a patient who is very bad, short of breath or with a lot of pain, then I don't begin with 20 mg of morphine but with 40 mg, and I say that I will come back after 6 hours and, then I will give another 40 mg. Then the patient often dies the same evening or the next morning. That is then the final stage. Then you fill on the forms that the patient died a natural death. Mind you I speeded things up a bit. I call this supportive policy; to me it's nothing more than that. (man 45-55 years old)*

Other GPs (8/30) explained that their main aim was to enhance the patient's quality of life and to lessen the patient's suffering by actively caring for and supporting the patient and the relatives. GPs valuing this approach did not strove to directly avoid dealing with euthanasia requests, but rather to prevent requests for euthanasia being made by enhancing the quality of life of their patients. They emphasized that it is important for the patient and the relatives to feel supported, and they therefore appeared to pay much attention to developing a caring relationship with the patient and being available especially when they were most needed by the patient.

*Delaying things is my own problem… But it has something to do with palliative care, which has to be very good. A request for euthanasia is only a request, but it is a request with a lot of implications. Making sure that the palliative care is very good is a question of knowledge and motivation. Your knowledge has to be very good, so then you know what you can do, and your motivation implies, that you are fully supporting the patient. That you also say: 'listen, I will come to visit you on Saturday and Sunday as well whenever you need me'. It is sometimes enough just to pay more attention. Then perhaps it will not be necessary to perform euthanasia so often. (man 55-65 years old)*

Some of these GPs stated that they had also realized that euthanasia could otherwise have occurred because they were feeling powerless as a GP and because they were not successful anymore in treating the patient's symptoms or alleviating the suffering. Therefore they strove to enhance their ability to care for the terminally ill so that they would be less often confronted with this kind of situation.

*Naturally we've all had the standard training, but we have also organised other post-schooling courses. You have to be very well informed about palliative care in order to be able to make a sound judgement about a euthanasia request. If a patient says: 'I want to die', there are a lot of important aspects. You then have to find out what the suffering actually is. It is also possible that the palliative care was inadequate, or that the doctor didn't know what he had to do. (man 45-55 years old)*

Furthermore, they explained that terminally ill patients often feel vulnerable and are not always able to make the appropriate decisions about their own situation. Therefore, it is important to deal with a request for euthanasia very cautiously, to establish how such a request had evolved, and to determine whether by improving the care or adjusting the treatment of symptoms it would be possible to restore the situation and to make euthanasia less desirable. They explained that since their attitude had changed they no longer had to perform euthanasia. However, they did not totally reject the idea that euthanasia could be necessary as a last resort.

*I´m approaching the patient in a different way, I now say 'You have an incurable illness, I know a lot about it and I would like to look after you, as soon as you are back home. Will you call me then, so that you can talk about what you can expect from me'. That is a very different story, people are now choosing for palliative care because I can offer it. In the past I could either do nothing or I could perform euthanasia, but now I can offer palliative care. I tell them and that is what they want. However, some of them still want euthanasia, and that is OK, but now nearly as many as in the past. (woman 45-55 years old)*

**Being open to consider a patient's request for euthanasia**

Other GPs (16/30) made clear that even if they would like to avoid to have to perform euthanasia they were prepared to carefully consider a patient's request for euthanasia. Most of them emphasized the seriousness and burden of having to deal with a request for euthanasia as a GP and appeared to approach euthanasia very cautiously. Their decision-making process concerning a patient's request for euthanasia was based on conscientiously balancing the necessity to perform euthanasia and respect for their own values. They emphasized that they had to be sure that they

would make the right decision about euthanasia.

*Yes I think it could sometimes be a sort of trap that can't be avoided. That in spite of everything you can offer, a terminal stage can be so heavy, perhaps too heavy for a patient. In fact, I always see it as an emergency exit. When I am talking about it with a patient I say 'yes we will consider it, if you don't want to go on any longer and if I have nothing more to offer you to make it better'. These are two important things for me.*
*If the patient says: 'I really don't want to go on any longer because I'm suffering so much from such or such a complaint and I can't live with this'. Then I have to say: 'Well, I have nothing more to offer, you're already having the maximum treatment. But I think it's important that patients ask for it themselves. (man under 45 years of age)*

These GPs explained that they therefore first had to establish that they were not able to alleviate the patient's suffering any further or to treat patient's symptoms effectively before they could focus on the patient's request for euthanasia. Some of them also stressed the importance for terminally ill patients of being free to choose euthanasia when their life-expectancy is very limited.

The GPs explained that even if it might be very difficult for them to have to cope with the patient's request and subsequently to perform euthanasia, they were prepared to extend their own limits. However, it was essential for them to be able to cope with the consequences of performing euthanasia.

*When do you have a clear conscience about it [euthanasia] as a physician?*

*When you feel that you have to deliver someone from his suffering, and I know that it could change from one moment to another, but you also don't want to create a problem for yourself. I mean, I also have to have a clear conscience about this issue… This is when I feel that I have no doubts about the respectability of this intervention. (man 45-55 years old)*

For the GPs, the decision-making process appeared to be directed not only at considering the rationale for euthanasia, but also preparing themselves in order to actually be able to perform euthanasia and to overcome their own personal barriers. It was, for instance, crucial for most of them to have enough time to think about the patient's request, not to be forced to

decide quickly, and to feel sufficiently emotionally detached from the patient's situation.

In their opinion, end-of-life care was mainly directed at the adequate treatment of symptoms. Some of them for example thought that the most significant developments concerning end-of-life care were related to the administration by pump of drugs such as morphine. Most of them explicitly stated that they did not believe that palliative care could influence the occurrence of requests for euthanasia. They explained, for example, that because the initiative for palliative care was taken by the physician and euthanasia was requested by the patient, this had to be seen as two individual processes that were evolving independently. Even if recent developments in palliative care have resulted in attention being paid to the psychosocial and existential problems of the terminally ill, palliative care should in their view never be seen as a substitute for euthanasia.

*I feel that there will always be situations in which somebody will have a lot of pain, that you can't do anything about, except by masking it with morphine or that other symptoms that are difficult to treat will develop, such as dyspnoea… You can do a lot with palliative care, make sure that someone receives good care, or home care, guiding someone very intensively with everything that is available. However, there will still be situations that you can't control. (man 55-65 years old)*

**Discussion**

Being confronted with requests for euthanasia was often a source of concern for GPs. Several approaches toward intentionally hastening a patient's death emerged. There were GPs who mainly want to consider other ways than EAS to lessen a terminally ill patient's suffering because of their own principles and because it might be too demanding to have to cope with a request for euthanasia and to perform euthanasia. Among them there also were GPs who emphasized the importance of enhancing the patients' quality of life and alleviating the suffering by caring for and supporting the patient and the relatives. These GPs were less often confronted with the necessity to consider euthanasia in order to relieve the suffering of a terminally ill patient.

Other GPs were prepared to consider a patient's request for euthanasia, but underlined the importance of being sure that no other options for alleviating the patient's suffering were available. When being convinced of the

necessity of euthanasia they were better able to extend their own limits related to hastening a patient's death intentionally, and were willing to perform euthanasia.

GPs who strove to consider other ways than EAS to shorten the suffering of terminally ill patients were concerned by their own opinions and values and also by their ability to cope with EAS. They make clear that having to face a request for EAS and to perform euthanasia might have an important (emotional) impact on a physician. Their approach shows how physicians when confronted with the unbearable suffering of a terminally ill patient and with requests for euthanasia strive to find a balance between lessening the suffering of a terminally ill patient and being able to remain attentive at their own opinions and values. Some of them appeared to not stress the importance of enquiring about the patient's expectations and wishes with regard to the end of life and above all to be concerned about assuring a 'peaceful' dying process, for instance by giving large doses of opioids. It is possible that due to lack of knowledge about palliative care they feel less able to care for the terminally ill patient and to actively address aspects of care that might contribute to the end-of-life quality. Other GPs who also strove to consider other ways than EAS to lessen the suffering of patients underlined the importance of caring and of supporting the patient and the relatives. They appeared to be concerned about protecting the patient, who they believed was often vulnerable and not always able to make an appropriate decision. They believed that it could be possible to make euthanasia less necessary by increasing the quality of care. They underlined the importance of palliative care and of maintaining or enhancing the patient's end-of-life quality and alleviating the suffering. In contrast with their feelings in the past they now felt less powerless when caring for the terminally ill, were more confident about their ability to address the patient's suffering through palliative care and were also more confident about the possibility to avoid or to postpone requests for euthanasia.

GPs who were prepared to consider a patient's request for euthanasia, and subsequently to hasten a patient's death intentionally, did not appear to actively try to avoid the development of a request for euthanasia through their care for the patient. Apparently, they accepted the fact that in order to relieve a patient's suffering and to respect the final wishes of a terminally ill patient it would sometimes be

necessary to perform euthanasia. They did not appear to choose for EAS because they did not feel confident about their ability to address the suffering of a patient in an other way. They underlined that they first have to be persuaded about the requests of the patient and that euthanasia might be the ultimate answer to the suffering. Results of other studies have also indicated that physicians often strive to make compromises when facing difficult situations.[21]

The results of this study show that it can be a profound experience for GPs to care for a terminally ill patient, on the one hand perceiving how meaningful it can be to care for the terminally ill, and on the other hand having to face the patient's suffering and trying to find the most appropriate way to lessen this suffering. GPs have to be carefully trained in order to be able to take a sensitive approach to the patient's wishes about end-of-life decisions. A context of openness about euthanasia will certainly encourage physicians to talk about their own experience of caring for the terminally ill and dealing with requests for euthanasia. In this respect they might find some support in developing a well-balanced approach to the suffering of the terminally ill and in coping with aspects related to the alleviation of this suffering that might be emotionally disturbing.

This study has several limitations. The descriptions of the attitudes of the GPs are based only on data collected by means of interviews. It is probable that, if data were also collected by means of observation a wider range of aspects related to the attitudes of the GPs might have been described.[12, 13, 22] Furthermore, it is important to realize that the aim of the study was only to investigate the experience of the GPs, and not the patient's experience or any other issues related to the relationship between the quality of end-of-life care and euthanasia. However, we believe that our data provide considerable insight into the experiences of GPs in alleviating the suffering of terminally ill patients and in dealing with requests for euthanasia. It has been described that physicians are mainly resolving their own sense of helplessness when granting a request for euthanasia.[10] However the results of the present study, in line with other studies,[8, 23] underline the importance of a physician's commitment in treating the suffering of terminally ill patients and of being persuaded that euthanasia might contribute to the quality of the dying process in order to cope with a request for euthanasia.

The results of the study show that the attitudes of GPs towards requests for euthanasia are mainly based on their opinions and feelings about (performing) euthanasia, their opinions about the relationship between palliative care and euthanasia, and their attitude towards a patient's preference with regard to end-of-life decisions. The complex interplay of these factors illustrates how GPs all strive in their own way to find a balance between their own values and the need to alleviate the suffering of terminally ill patients.

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| Table 1 Characteristics of participating general practitioners | | N=28 [1] |
|---|---|---|
| Gender | Male | 20 |
| | Female | 8 |
| Age | < 45 | 5 |
| | 45 - 55 | 14 |
| | 55 - 65 | 9 |
| Years of experience as a general practitioner | 1-9 | 4 |
| | 10-20 | 11 |
| | > 20 | 13 |
| Religious belief | Yes | 8 |
| | | |
| Practice | Working alone | 12 |
| | Working in association | 16 |
| Localisation of general practice | City | 14 |
| | Rural community | 4 |
| | Mixed | 9 |
| | Other | 1 |
| | | |
| Had received explicit requests for euthanasia in the past | | 25 |
| Had ever performed euthanasia in the past | | 18 |
| | | |
| Attitudes towards euthanasia | Restrictive | 13 |
| | Permissive | 4 |
| | No change | 11 |
| | | |

[1] 2 missing cases
[2] Questions about attitudes asked during the interview for the nationwide study

| BOX 1 Main topics of interview |
| --- |
| - GP's experiences as a physician |
| - The kind of general practice and the patient population |
| - GP's experience with caring for terminally ill patients |
| - GP's experience with euthanasia |
| - Requests for euthanasia from patients |
| - (Changes in) attitudes with regard to end-of-life care and euthanasia |
| - Opinion about the relationship between palliative care and euthanasia |
| - Opinion about further developments with regard to end-of-life care |

# *Chapter 7*

# *Physicians' opinions on palliative care and euthanasia in the Netherlands*

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**Abstract**

*Background*

In recent decades significant developments in end-of-life care have taken place in the Netherlands. There has been more attention for palliative care and alongside the practice of euthanasia has been regulated

*Goals*

The aim of this paper is to describe the opinions of physicians with regard to the relationship between palliative care and euthanasia, and determinants of these opinions.

*Methods*

Design: Cross-sectional.

Subjects: Representative samples of physicians (n= 410), relatives of patients who died after EAS (n= 87), and members of the ERCs (n= 35).

Measurements: Structured interviews with physicians and relatives of patients, and a written questionnaire for the members of the ERCs.

*Results*

Approximately half of the physicians disagreed and one third agreed with statements describing the quality of palliative care in the Netherlands as sub-optimal and describing the expertise of physicians with regard to palliative care as insufficient. Almost two third of the physicians disagreed with the suggestion that adequate treatment of pain and terminal care make euthanasia redundant. Having a religious belief, being a nursing home physician or a clinical specialist, never having performed euthanasia and not wanting to perform euthanasia were related to the belief that adequate treatment of pain and terminal care could make euthanasia redundant.

*Conclusion*

The study results indicate that most physicians in the Netherlands are not convinced that palliative care can always alleviate all suffering at the end of life and believe that euthanasia could be appropriate in some cases.

**Introduction**

In the Netherlands of all deaths (n= 142000, year 2003) about 33% occurred at the hospital, about 25% at home, en about 20% at a nursing home. Of the patients, between 20 and 79 years old, who died of cancer in the year 2003 about 35% died at the hospital, about 50% at home, about 8% at a nursing home and 7% at an other place.[1] In recent decades significant developments in end-of-life care have taken place. One major development concerned the regulation of the practice of euthanasia and physician-assisted suicide (EAS) in order to establish legal control and to provide public oversight. Developments in the notification procedure resulted in 1998 in the establishment of regional Euthanasia Review Committees (ERCs), with a physician, a lawyer and an ethicist as members, who advise the Public Prosecutor. In 2002 a law was enacted to legalize EAS provided that the official requirements for prudent practice were met. Since then all reported cases of euthanasia are reviewed by the ERCs, and only the cases in which the requirements for prudent practice were not met are reported to the Public Prosecutor.[2] Another major development was that more attention was paid to the improvement of care for the terminally ill. In 1996 the Minister of Health formulated a policy for the further development of palliative care, which has led to the proliferation of palliative care services, such as terminal care units in nursing homes, hospices and other health organizations caring for the terminally ill. It also aims to increase expertise in the field of terminal care.[3,4]

Experiences and attitudes with regard to end-of-life medical decisions have been studied regularly in the Netherlands during the past decade.[4-8] However little is known about the relationship between opinions with regard to palliative care and euthanasia and how developments in palliative care influence these opinions.[9-11] Attitudes and opinions with regard to euthanasia are closely related to experiences,[12,13] and it is therefore probable that these opinions differ between physicians and the general public,[14-16] as well as between physicians with different types of clinical experience.[12,17] Personal characteristics such as religious beliefs and older age, have been found to be related to disapproving of EAS.[12,15,18]

This paper focuses on opinions of physicians concerning the relationship between palliative care and euthanasia, and determinants of these opinions. In light of this we also

compared, where possible, physicians' opinions with those of other groups of people who are involved in end-of-life care: relatives of the patients, and members of the ERCs, and we looked for physicians characteristics that might be related to their opinions.

## Methods

*Participants and materials*

This paper presents data from a nationwide study of physicians, data obtained from interviews with relatives of patients who died after their request for EAS had been granted, and data collected through questionnaires sent to members of the ERCs. These studies have all been previously described in more detail elsewhere.[2,7,19]

The interview schedules and questionnaire addressed experiences of and attitudes about end-of-life decision making and were derived and adapted from previous studies about end-of-life decision making in the Netherlands.[5,8] In all the studies the opinions of the participants were based on their (dis)agreement with statements concerning medical end-of-life decisions and the quality of palliative care. The choice of answers was as follows: totally disagree, disagree, undecided, agree, totally agree.

*Interviews with physicians*

In the nationwide study concerning the attitudes and experiences of physicians with regard to medical end-of-life decisions selected random samples of physicians stratified according to specialty were interviewed in 2001.[7]

The selection criteria were that the physicians were actively practising medicine at the time of the interview, and also in the previous 2 years in the registered specialty and in the same place. Addresses from the professional registers were used to select the physicians. We included general practitioners, nursing home physicians and clinical specialists (surgeons, cardiologists and specialists in internal medicine, pulmonology, and neurology). Physicians in the specialties that were included attend all together almost all deaths in the Netherlands.

In 2001 physicians were interviewed personally by experienced physicians, who were specifically trained for this purpose.

Table 1 Opinions of physicians with regard to statements about palliative care in the Netherlands

| | Physicians (n=410) %[1] & [95% CI] | | |
|---|---|---|---|
| | Disagree | Undecided | Agree |
| The quality of palliative care is sub-optimal in the Netherlands * | 50 [41-58] | 20 [14-24] | 30 [24-36] |
| Because in the Netherlands much attention has been paid to the regulation of euthanasia, too little attention has been paid to other possibilities to reduce suffering at the end of life * | 49 [41-57] | 10 [06-13] | 41 [34-49] |
| Because of insufficient knowledge about palliative care physicians in the Netherlands are frequently not able to judge whether there are any other alternatives for treatment * | 50 [41-57] | 14 [09-17] | 36 [29-43] |

*Originally measured on a 5–point scale: totally agree, agree, undecided, disagree, totally disagree, Scores totally agree and agree are summarised as agree and scores totally disagree and disagree are summarised as disagree.
[1] (Weighed)

*Interviews with relatives of patients*

In the study investigating the experiences and opinions of relatives,[19] we interviewed the relative who had been most involved with the patient. The relatives were first approached by the physician who had attended the death of the patient and had already participated in the interview study concerning the experience of physicians with regard to the EAS notification procedure. Of the 167 eligible relatives, 97 (58%) were approached by the physician, and for those who were willing to participate in the study an appointment was made for an interview. Finally, 87/97 (90%) relatives agreed to be interviewed. The interview schedule was specifically developed for this study and pre-tested

with 4 relatives of patients who died after EAS some years earlier. The interviews were held in the home of the relative, and conducted by interviewers who were specifically trained for this purpose between October 2002 and March 2003.

*Questionnaire for members of the Regional Review Committees*

The members of the ERCs, their deputies, and the secretaries of each committee were approached in November 2002, in order to assess their experiences and opinions with regard to EAS by means of a questionnaire. The questionnaire was specifically developed for this study.[20] Of the 35 members who were approached, 34 returned a fully completed questionnaire.

*Statistical analyses*

Descriptive statistical analyses, including frequency, means, range and standard deviation, were performed, when appropriate on variables related to opinions, such as characteristics of physicians and experiences of physicians with EAS. Confidence Intervals (95%) were computed for all descriptive statistics. All percentages concerning the opinions of physicians were weighted for differences in sampling fractions for the different specialties and non-response.

For the statements related to opinions, the answer categories 'totally agree' and 'agree' were combined to form one category 'agree', and the answer categories 'totally disagree' and 'disagree' were combined to form one category 'disagree'. Univariate analysis, using logistic regression, was applied in order to assess factors related to a positive opinion of physicians with regard to the statement about the quality of palliative care in the Netherlands and the statement about the relationship between palliative care and euthanasia.

**Results**

*Characteristics of the participants*

Of the 410 physicians who participated in the study, 310 (76%) were male and 171 (43%) had a religious belief (other characteristics are described in Tables 3 and 4). Of the 35 members of the ERCs, 8 were physicians, 10 were jurists, 10 were ethicists and 7 were secretaries (also jurists); 16 (46%) were male and 19 (54%) had a religious belief. Of the 87 relatives, 36 (41%) were male, 55 (63%) were a partner of the patient, 24 (28%) were a child of the patient, and 40 (46%) had a religious belief.

*Physicians' opinions with regard to the quality of palliative care and euthanasia*

Approximately half of the physicians disagreed with the following statements: 'The quality of palliative care is sub-optimal in the Netherlands' (50%), 'Because in the Netherlands much attention has been paid to the regulation of euthanasia, too little attention has been paid to other possibilities to reduce suffering at the end of life' (49%), and 'Because of insufficient knowledge about palliative care, physicians in the Netherlands are frequently not able to judge whether there are any other alternatives for treatment' (50%). Approximately one third of the physicians agreed with these statements (30%, 41% and 36%, respectively).

With regard to opinions towards the relationship between palliative care and euthanasia 61% of the physicians disagreed with the statement 'Adequate treatment of pain and terminal care make euthanasia redundant', while 33% agreed (Table 2). Table 2 shows that physician's opinions on this statement differ from the opinions of members of ERCs and relatives of patients. The latter two groups more frequently disagree (85% and 84%), and less frequently agree (6% and 10%) with the statement than physicians.

Table 2 Opinions of physicians, members of the regional Euthanasia Review Committees (ERCs) and relatives of patients with regard to a statement about the relationship between palliative care and euthanasia

| Adequate treatment of pain and terminal care make euthanasia redundant* | Physicians (n=410) %[1] & [95% CI] | | | ERC Members (n=34) † % & [95% CI] | | | Relatives of patients (n=86) † % & [95% CI] | | |
|---|---|---|---|---|---|---|---|---|---|
| | Disagree | Undecided | Agree | Disagree | Undecided | Agree | Disagree | Undecided | Agree |
| | 61 | 6 | 33 | 85 | 9 | 6 | 84 | 6 | 10 |
| | [52-71] | [03-08] | [26-39] | [68-95] | [01-23] | [01-19] | [74-90] | [01-13] | [04-18] |

*Originally measured on a 5 – point scale: totally agree, agree, undecided, disagree, totally disagree. Scores totally agree and agree are summarised as agree and scores totally disagree and disagree are summarised as disagree. [1] (Weighed) † 1 missing case

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*Factors associated with physicians' opinions about the quality of palliative care*

Table 3 shows the relationship between the characteristics of the physicians and their agreement with the statement: 'The quality of palliative care is sub-optimal in the Netherlands'.

The results of the univariate analysis show that the physicians who never will perform euthanasia and the physicians who never had performed euthanasia, but would be prepared to do so, were twice as likely to agree with the statement (OR= 2.15 and OR= 2.14, respectively) compared to the physicians who had performed euthanasia. The probability of agreement with the statement was higher in nursing home physicians (OR= 1.73) and in clinical specialists (OR= 2.3) than in general practitioners, and somewhat higher in physicians with more than 4 years of experience (OR between 1.19 and 1.41), and physicians with a religious belief (OR=1.28). The church affiliation of physicians did not appear to influence their opinion with concern to the quality of palliative care. With regard to gender and the number of times euthanasia had been performed the previous two years the results were inconclusive (OR= 1.04 and OR= 1.05, respectively).

*Factors associated with physicians' opinions about the relationship between palliative care and euthanasia*

Table 4 shows the relationship between the characteristics of the physicians and their agreement with the statement: 'Adequate treatment of pain and terminal care make euthanasia redundant'.

Results of the univariate analysis show that physicians with a religious belief (OR= 2.47), nursing home physicians (OR= 1.65) and clinical specialists (OR= 1.42) were more likely to agree with the statement. Physicians who would never perform euthanasia were more likely to agree with the statement (OR= 1.57) than physicians who said that they would be prepared to perform euthanasia (OR= 1.04) and physicians who had performed euthanasia (OR= 1). Agreement with the statement was less likely in physicians who were male (OR= 0.73), who had more years of experiences (OR between 0.36 and 0.73), and who had received an explicit request for euthanasia (OR= 0.71).

Table 3 Association between physician characteristics and agreement with the statement: 'The quality of palliative care is sub-optimal in the Netherlands'

| | Total[1] (n=406) n | Disagree [2] (n=183) % | Undecided (n=86) % | Agree[2] (n=137) % | Univariate analysis[3] OR & [95% CI] of agreement with the statement | |
|---|---|---|---|---|---|---|
| Gender[4] | | | | | | |
| Male | 306 | 49 | 21 | 30 | 1 | |
| Female | 99 | 54 | 15 | 31 | 1.04 | [0.94-1.15] |
| Age[2] | | | | | | |
| <45 | 138 | 45 | 23 | 31 | 1.14 | [1.04-1.26] |
| ≥45 | 260 | 52 | 17 | 31 | 1 | |
| Religious beliefs[2] (Yes) | 169 | 43 | 26 | 31 | 1.28 | [1.17-1.40] |
| Roman Catholics | 77 | 36 | 30 | 34 | 0.72 | [0.30-1.74] |
| Protestants | 57 | 39 | 26 | 35 | 0.70 | [0.28-1.78] |
| Others | 35 | 39 | 11 | 50 | 1 | |
| (No) | 224 | 54 | 15 | 31 | 1 | |
| Medical speciality | | | | | | |
| General practitioner | 124 | 58 | 17 | 25 | 1 | |
| Nursing home physician | 77 | 48 | 16 | 36 | 1.73 | [1.47-2.03] |
| Clinical specialist | 208 | 37 | 26 | 37 | 2.30 | [2.10-2.25] |

Table 3 Association between physician characteristics and agreement with the statement: 'The quality of palliative care is sub-optimal in the Netherlands'

| | Total[1] | Disagree[2] | Undecided | Agree[2] | Univariate analysis | |
|---|---|---|---|---|---|---|
| Years of experience as a physician[2] | | | | | | |
| 0-4 years | 41 | 49 | 26 | 25 | 1 | |
| 5-9 years | 67 | 50 | 19 | 31 | 1.19 | [0.97-1.45] |
| 10-14 years | 80 | 52 | 18 | 30 | 1.13 | [0.94-1.37] |
| 15-19 years | 91 | 54 | 15 | 31 | 1.22 | [0.93-1.36] |
| 20-24 years | 49 | 49 | 17 | 34 | 1.37 | [1.11-1.68] |
| 25 years or more | 65 | 44 | 25 | 32 | 1.41 | [1.16-1.71] |
| Ever received an explicit request (Yes) | 279 | 52 | 17 | 31 | 0.86 | [0.78-0.96] |
| (No) | 126 | 42 | 29 | 29 | 1 | |
| Number of cases of euthanasia the previous 2 years Mean, (SD) [range] | | 2 (2.07) [0-20] | 2.5 (3.2) [0-25] | 2.26 (2.8) [0-13] | 1.046 | [1.02-1.06] |
| Experiences related to euthanasia (EAS) | | | | | | |
| - Never have and never will perform EAS | 59 | 33 | 27 | 39 | 2.15 | [1.88-2.46] |
| - Never have performed EAS but would be prepared to do so | 153 | 41 | 21 | 38 | 2.14 | [1.95-2.36] |
| - Have performed EAS | 191 | 51 | 20 | 29 | 1 | |

[1] 4 missing, [2] Scores totally agree and agree are summarised as agree and scores totally disagree and disagree are summarised as disagree, [3] n= 320 cases included,[4] Various number of missing values

**Discussion**

Approximately half of the physicians disagreed and one third agreed with statements describing the quality of palliative care as sub-optimal and describing the expertise of physicians with regard to palliative care as insufficient. Almost two third of the physicians disagreed with the suggestion that adequate treatment of pain and terminal care make euthanasia redundant, and an even greater majority of members of the ERCs and relatives of patients disagreed with this suggestion. Having a religious belief, being a nursing home physician or a clinical specialist, never having performed euthanasia and not wanting to perform euthanasia were related to the belief that adequate treatment of pain and terminal care could make euthanasia redundant.

A limitation of this study is that because of the limited number of ERCs members and relatives of patients included into the study it was not possible to assess factors that were related to their opinions concerning the relationship between palliative care and euthanasia.

It is known that physicians in the Netherlands, compared with their colleagues in several European countries and Australia receive palliative care training relatively frequently.[21] However, the results indicate that a substantial number of physicians were critical about the quality of palliative care; 30% of the physicians were not convinced that the quality of palliative care was optimal, more than 40% believed that too little attention had been paid to the further development of end-of-life care, and only 50% believed that physicians in the Netherlands had enough expertise to judge whether there were any other alternatives for treatment. This critical opinion about the quality of palliative care might also be a sign of considerable appraisal of the significance of palliative care.

Table 4 Association between physician characteristics and agreement with the statement: 'Adequate treatment of pain and terminal care make euthanasia redundant'

| | Total[1] (n=408) n | Disagree[2] (n=236) % | Undecided (n=28) % | Agree[2] (n=144) % | Univariate analysis[3] OR & [95% CI] of Agreement with the statement | |
|---|---|---|---|---|---|---|
| Gender[4] | | | | | | |
| Male | 308 | 63 | 6 | 31 | 0.73 | [0.67-0.81] |
| Female | 99 | 57 | 4 | 39 | 1 | |
| Age[2] | | | | | | |
| <45 | 137 | 56 | 10 | 34 | 0.84 | [0.77-0.91] |
| ≥45 | 259 | 64 | 4 | 32 | 1 | |
| Religious beliefs[2] (Yes) | 170 | 48 | 8 | 44 | 2.47 | [2.28-2.69] |
| Roman Catholics | 77 | 47 | 9 | 44 | 0.70 | [0.31-1.60] |
| Protestants | 56 | 56 | 11 | 33 | 0.44 | [0.18-1.07] |
| Others | 37 | 41 | 5 | 54 | 1 | |
| (No) | 224 | 70 | 4 | 26 | 1 | |
| Medical speciality | | | | | | |
| General practitioner | 125 | 66 | 4 | 30 | 1 | |
| Nursing home physician | 77 | 53 | 7 | 40 | 1.65 | [1.42-192] |
| Clinical specialist | 208 | 55 | 9 | 37 | 1.42 | [1.30-1.54] |

Table 4 Association between physician characteristics and agreement with the statement: 'Adequate treatment of pain and terminal care make euthanasia redundant'

| | Total[1] | Disagree[2] | Undecided | Agree[2] | Univariate analysis | |
|---|---|---|---|---|---|---|
| Years of experience as a physician[2] | | | | | | |
| 0-4 years | 41 | 52 | 1 | 47 | 1 | |
| 5-9 years | 67 | 61 | 14 | 25 | 0.44 | [0.37-0.55] |
| 10-14 years | 82 | 56 | 6 | 38 | 0.73 | [0.62-0.86] |
| 15-19 years | 91 | 67 | 3 | 29 | 0.47 | [0.40-0.56] |
| 20-24 years | 49 | 69 | 9 | 23 | 0.36 | [0.30-0.43] |
| 25 years and longer | 65 | 61 | 0 | 39 | 0.70 | [0.59-0.82] |
| Ever received an explicit request (Yes) | 281 | 64 | 5 | 31 | 0.71 | [0.65- 0.78] |
| (No) | 126 | 56 | 6 | 38 | 1 | |
| Number of cases of euthanasia the previous 2 years mean, (SD) [range] | | 2.32 (2.75) [0-25] | 1.37 (1.04) [0-3] | 1.96 (2.39) [0-14] | 0.94 | [0.92-0.96] |
| Experiences related to euthanasia (EAS) | | | | | | |
| - Never have and never will perform EAS | 60 | 53 | 6 | 41 | 1.57 | [1.39-1.76] |
| - Never have performed EAS but would be prepared to do so | 153 | 61 | 8 | 31 | 1.04 | [0.95-1.14] |
| - Have performed EAS | 192 | 64 | 4 | 32 | 1 | |

[1] 2 missing, [2] Scores totally agree and agree are summarized as agree and scores totally disagree and disagree are summarized as disagree , [3]n=365 cases included,[4] Various number of missing values

As described elsewhere,[12,15,22] the study results show that the opinions of physicians with regard to the relationship between palliative care and euthanasia are influenced by medical specialty and religious beliefs. Furthermore, the number of physicians agreeing with the statement that adequate treatment of pain and terminal care make euthanasia redundant remained unchanged between 1995 and 2001.[8] In a European study, more than 50% of the physicians in the Netherlands agreed with a similar but less strict statement, a percentage that was comparable to the results for physicians in Belgium, and Australia but less than for physicians in Denmark, Italy, Sweden and Switzerland.[23] Furthermore, as illustrated by the finding that physicians might be in favour of the legalization of euthanasia in general, but not willing to grant explicit requests for euthanasia from patients, the opinions and experiences have to be considered separately.[12] It is also possible that by the increased knowledge about and possibilities for palliative care physicians are better able to judge whether there are any other alternatives for treatment. Therefore, they might be less inclined to grant requests for EAS than in the past.[20]

Important differences between the opinions of physicians and those of members of the ERCs and relatives of patients became apparent in the study. Members of the ERCs and the relatives of the patients thought less often than the physicians that there was a relationship between palliative care and euthanasia.

There is evidence that opinions about euthanasia are influenced by experiences.[12,13,24,25] Due to their concrete encounters with end-of-life situations, physicians are probably those who are best able to assess the adequacy of care and the possibilities to alleviate suffering in the terminally ill. On the other hand, because the relatives are closely involved in the patient's situation, they might feel that euthanasia is the only way to alleviate the suffering of the patient and is a sign of respect for a patient's wish.[19,20] Also a majority of ERCs members disagree with the statement 'Adequate treatment of pain and terminal care make euthanasia redundant'. It is probable that in their review of euthanasia cases they have observed that requests can exist while pain and other symptoms were adequately treated.[20] It is also possible that members of the ERCs are generally supportive of euthanasia.

This study did not take into account the way in which the legal regulation of euthanasia in the Netherlands affects the opinions of the physicians. However, it has been reported that since the legal regulation of assisted-death, e.g. in Oregon after the introduction of the 'Death with Dignity Act', increased efforts have been made to enhance the quality of life of terminally ill patients and for physicians to improve their own knowledge about end-of-life care.[26,27]

Compared to other medical specialists, general practitioners more often accepted the necessity of euthanasia. They are the physicians who are most often confronted with requests for euthanasia from patients and those who perform euthanasia the most.[7,8,20] It is probable that the opinions of general practitioners in favour of euthanasia are related to their experience of powerlessness and inability to alleviate the suffering in any other way when a patient requests euthanasia. The ability of physicians to alleviate a patient's suffering has been found to be related to their attitude towards euthanasia.[15,24,28]

The results of this study indicate that in the Netherlands, where euthanasia is openly discussed and legally regulated, physicians still appear to have a balanced opinion with regard to euthanasia. However, they seem not to be convinced that palliative care can always alleviate all suffering at the end of life and believe that euthanasia could be appropriate in some cases.

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# *Chapter 8*

# *Discussion and conclusions*

## 8.1 Introduction

The aim of this thesis was to gain insight into medical end-of-life decisions in the context of terminal care. The following research questions were addressed :

1. What are the (health) problems that terminally ill (cancer) patients encounter during the final months of their life, and how are they treated and cared for?
2. Which wishes related to medical end-of-life decisions, and more specifically with regard to euthanasia and physician-assisted suicide do terminally ill (cancer) patients have? Which factors are related to the development of these wishes?
3. What are physicians´ attitudes and experiences with regard to terminal care, and medical end-of-life decisions, especially concerning euthanasia and physician-assisted suicide?

The six studies that were carried out in order to address these research questions have been briefly described in the Introduction of this thesis (Chapter 1), and subsequently in more detail in the following chapters that also present the results of the different studies (Chapter 2 to Chapter 7). This last part of the thesis describes the results of the studies in relation to the main research questions. First, methodological aspects of the different studies will be considered, and then the major findings of the studies will be discussed. Subsequently, the conclusions will be summarized, the implications of the results with regard to the development of health policies and practice are discussed, and recommendations are made for further research on terminal care.

## 8.2 Methodological considerations

All the studies described in this thesis took place within the context of the third nationwide study of medical end-of-life decisions.[1] The primary participants in the third nationwide study were physicians, who were interviewed about several specific situations with regard to medical end-of-life decisions. Furthermore, relatives of patients and members of the Euthanasia Review Committees (ERCs) were also asked about their experiences and attitudes. A limitation of the study is the lack of a patient perspective.

Developments in terminal care have mainly been directed at patients suffering from cancer and furthermore, most of the requests for EAS are made by cancer patients. Most of the data presented in this thesis (Chapter 2 to Chapter 4) concern terminally ill patients who suffered

from cancer. The results of these studies can therefore not be generalized immediately to patients suffering from other terminal illnesses. However, the data presented in Chapter 5, 6 and 7 do not only concern patients suffering from cancer.

Prospective study designs probably are the best way to gain more insight into terminal care and medical end-of-life decisions.[2-4] However, the possibilities of performing a prospective study with a population of frail terminally ill patients are often limited because of the ethical and methodological difficulties encountered when long and intensive participation is required from the respondents.[2] Fortunately, within this thesis a prospective study design could be used in order to describe the development of health-related problems and requests of terminally ill cancer patients concerning the medical end-of-life decisions (Chapter 2 and Chapter 3). The data in this study were collected from physicians. In order to ensure the accuracy and reliability of the data, the participating physicians were asked to report during the interview, and also in each questionnaire, the number of visits they had made to the patient since the previous assessment, and when they had visited the patient for the last time. In this way it was also possible to focus the questions contained in the questionnaire on a specific period of time and a specific moment.

Patients had to meet certain specific criteria to be included in the prospective study by the attending physician. One of these criteria concerned the life-expectancy of the patient, which had to be a minimum of one week and no longer than three months after inclusion. However, as the survival period for most patients was shorter than expected, the results concerning the final months of the life of terminally ill patients were less comprehensive than one would expect from a prospective study design. Therefore, the analysis of the data focused only on the time of the interview (inclusion) and the time shortly before death (data from the last questionnaire that was completed shortly before the death of the patient), so the results do not provide complete insight into the development of (aspects related to the) health problems and medical end-of-life decisions during the final months of the life of a terminally ill patient.

Only a few patients who had been included by their attending physician in the prospective study died after the physician had granted their request for euthanasia. In order to describe

determinants of requests for EAS and to gain insight into the decision-making process concerning a request for EAS, it was necessary to obtain more data on requests for EAS that had been granted (Chapter 4). Therefore, we decided to compare the patients who did not request EAS, described in the prospective study, with patients who died after their request for EAS had been granted, described retrospectively. However, it is possible that the questions asked in the two groups referred to somewhat different points of time in the illness trajectory. The data on patients who died after euthanasia had been performed refer to the period during which the physician was considering the request, which is generally earlier in the course of the illness than the time of the physician's last visit before the death of a patient who did not request euthanasia. Therefore, as it is probable that the symptoms would have been more severe in patients who died of euthanasia if in this group it had also been possible to use data relating to the time of the physician's last visit before the death of the patient.

The main limitations of the sub-study describing the influence and meaning of EAS at the end of a terminally ill patient's life (Chapter 5) are related to the use of proxy reports,[5] and the fact that selection bias might have taken place because the participants in this study, i.e. the relatives of the patients, were asked to participate by the attending physician. It is not ruled out that the physicians have only selected unproblematic cases e.g. relatives of patients who were satisfied about end-of-life care. However, we asked the physician to invite the relative who had been most involved in the patient's situation to participate, and in this way we probably obtained the most comprehensive insight into the patient's situation. This might have enhanced the reliability of the results. The results of the study furthermore indicate that the selection of non-problematic cases probably only occurred in a limited number of the relatives.

Qualitative studies based on interviews are well-suited to describe the experiences of the participants, and are generally appraised because of the internal validity of the results.[6] In the present study, investigating the experiences of general practitioners when dealing with requests for euthanasia (Chapter 6) the emerging themes could be described in sufficient detail and richly illustrated by interview quotes. These emerging themes could also be recognized by the

researchers. However, the results apply to general practitioners in the Netherlands, and even though the participants in the study were selected from a representative sample of physicians, the results should be generalized with caution.

Only a limited number of characteristics of the different participants in the study focusing on opinions with regard to palliative care and EAS (Chapter 7) could be assessed and compared. However, the originality of the study lies mainly in the fact that determinants of the physicians´ opinions were described and that their opinions were compared with those of relatives of the patients and members of the Euthanasia Review Committees (ERCs).

The different studies described in this thesis did not assess medical end-of-life decisions directly from the point of view of the patients. However, confidence in the results might be enhanced by the fact that the responses of different study participants, namely those of the physicians and the relatives, concerning some important issues were similar, e.g. the patient's reasons for requesting euthanasia, the importance of dignity, and patient concerns.

## 8.3 Major findings

### *8.3.1 Health problems and care in terminally ill cancer patients*

*Symptoms of terminally ill cancer patients*

The results of the prospective study (Chapter 2) indicate that the terminally ill cancer patients who were included in the study suffered from many (severe) physical and psychosocial symptoms one to two months before dying and also shortly before their death. At both points in time the most prevalent physical symptoms were fatigue, feeling unwell, ADL-dependency, loss of appetite, and pain. The most prevalent psychosocial symptoms were problems with coping and accepting dependency, anxiety, and feelings of powerlessness. Only a few symptoms appeared to improve shortly before death, when their frequency or severity decreased e.g. pain, nausea, coughing, problems coping, and anxiety. There was a deterioration in many symptoms shortly before death. The prevalence and/or the severity of some symptoms in these patients, e.g. loss of appetite, fatigue, ADL-dependency, and feeling unwell, increased considerably between the moment of inclusion and shortly before death. This indicates

that terminally ill patients become increasingly distressed during the final phase of their life. A decline in the health of patients as death approaches has also been described in other patient populations.[7]

It has been reported that the number and severity of symptoms mainly affect the quality of life of patients by limiting their ability to live their own life and by reducing their sense of control.[8-9] The interrelated physical, psychosocial and existential consequences of symptoms in patients with a terminal illness might be a threat to their personal life, their feelings of personal integrity, and significant inter-personal relationships, and in this way cause suffering that is sometimes described as a process of personal disintegration and alienation.[10-17]

*Terminally ill patients´ concerns*

The high prevalence of concerns in these patients indicate that they were confronted with a great amount of uncertainty and apprehension about their future. The concerns were mainly related to symptoms such as pain and dyspnoea, ADL-dependency, and loss of dignity (Chapter 3 and Chapter 5). Some concerns were very prevalent, even if the patient did not yet appear to suffer yet from this symptom or condition, e.g. more patients who were not yet dependent were concerned about becoming ADL-dependent than patients who were already dependent (Chapter 3).

It might be difficult to establish how concerns affect a patient's quality of life and in which way patients suffer from these concerns. However, as a concern can be considered as an expression of the more intimate thoughts of patients that can usually not be communicated easily and rapidly with physicians, the results of the prospective study (Chapter 3) indicating that at the time of inclusion the patients already had an important number of concerns, might imply that patients had been confronted a long time with concerns and thus a limitation in their quality of life.[18] The results of the present study also show that concerns are related to a wide range of psychosocial symptoms, e.g. problems with coping, depressive feelings, feelings of powerlessness and feelings of meaninglessness. High numbers of concerns in terminally ill patients have been related to feelings of uncertainty and to psychological distress, and more specifically to depressive feelings and feelings of anxiety.[19] It has been reported that the worries of terminally ill patients about loss of quality of life, e.g. no longer being able to participate in enjoyable

activities, are mainly related to their suffering.[20] It is probable that concerns constitute an important aspect of the feelings of hopelessness and meaninglessness of terminally ill patients.

*Treatment of symptoms and patient care*

With regard to the treatment of symptoms, it appeared that two months before death and shortly before death almost all physical symptoms that were assessed, e.g. pain, nausea, and dyspnoea, were treated, while psychosocial symptoms such as depressive feelings, anxiety, and confusion were less often treated (Chapter 2). It is difficult to determine whether a high prevalence of symptoms is due to the quality of the treatment or to symptoms that are very difficult to treat. With regard to psychosocial symptoms, it has regularly been reported that these are less frequently treated than physical symptoms. However, the study results do not always take into account the fact that attention might be paid to the psychosocial symptoms of a terminally ill patient by other (para)medical disciplines or by the patient's relatives or friends. The results of the present study show that, especially shortly before the death of the patient, informal carers were increasingly involved in caring for the patient (Chapter 2).

It is furthermore possible that, as physical and psychosocial symptoms are sometimes inter-related, the treatment of physical symptoms contributes to the psychosocial well-being of the patient.[21, 22] For example, it has been reported that less physical symptoms might make patients feel more free to think about their concerns and to resolve their psychosocial problems. This could support them in increasing their feeling of self-control, restoring their personal integrity, or finding meaning.[22,23] However, the data presented here (Chapter 2) were not collected for the purpose of describing in more detail the background and intention of medical treatment. In any case, a high prevalence of unrelieved symptoms underlines the need for further development of terminal care.[12, 17-21]

*The dying process*

According to the attending physicians, the dying process appeared to be peaceful for most patients (Chapter 2). Apparently, the high prevalence of potentially disturbing symptoms did not affect the dying process. It has sometimes been reported that concerns affect the patient much more than

symptoms.[20] It is possible that before dying patients are better able to "let go" if they are able to distance themselves from their problems and concerns. Furthermore, because most terminal patients are aware they are dying, they can prepare themselves and try to accept they approaching death. Strengthening relationships with loved ones has also been described as an essential aspect of the quality of the end of a patient's life.[21] The results of the present study (Chapter 2) also indicate that a good relationship between patients and significant others promotes the quality of the end of the patient's life. It might therefore be essential, when possible, to encourage care provided by loved ones and to promote favourable conditions in which to say good-bye, in order to contribute to a peaceful dying process.

### *8.3.2 Terminally ill patients´ requests with regard to medical end-of-life decisions*

*Requests to forgo a potentially life-sustaining medical treatment*

Decisions to forgo medical treatment are frequently made.[24] In general, these decisions do not concern high-technology treatment, and mostly they do not result in shortening the patient's life to any great extent.[24] It is known that these decisions are usually shared between the caregivers and the patient.[25] From the results of the present study it became clear that the reasons for a request from a terminally ill cancer patient to forgo a potentially life-sustaining treatment, e.g. to refuse all medical treatment excepted for painkillers, were usually general weakness and hopeless suffering (Chapter 3). Patients who made a request to forgo treatment appeared to have a less drastic deterioration in their health than patients who requested EAS, as shown by the development of their symptoms (Chapter 3).

Furthermore, the prevalence and number of symptoms and of most concerns was lower in patients who made a request to forgo a potentially life-sustaining treatment than in patients who requested EAS. However, the prevalence of some symptoms, such as loss of appetite, fatigue, and ADL-dependency, was very high in patients who made a request to forgo treatment.

*Development of requests for EAS*

The results of the present study indicate that a patient's requests for EAS are based on several inter-related factors, e.g. the patient's symptoms, attitude to autonomy, way of dealing

with concerns, way of dealing with deterioration, and feeling of dignity (Chapter 3, Chapter 4 and Chapter 5). Most patients (79%) who died after EAS had been performed had expressed their wishes with regard to medical end-of-life decisions before they became ill. Already, in the absence of a terminal illness, they had thought about circumstances at the end of their life that they probably not want to deal with and for which they probably would request EAS (Chapter 5).

The data presented in Chapter 5 show that it took rather a long period of time to develop a request for euthanasia and to express it explicitly to the physician. It was often between one week and three months before death that patients made an explicit request for EAS (Chapter 5). It is possible that, due to some specific circumstances, such as an episode of deterioration, or an increase in the number of physical and psychosocial symptoms and concerns (Chapter 3), terminally ill patients who have known for quite a long time that their prognosis is poor, become more certain about their wish and therefore find it easier to make an explicit request for EAS to their attending physician (Chapter 5). The study results (Chapter 3) indicate that as the disease evolved, patients became more resolute in their wish concerning a medical end-of-life decision. We observed, for instance, that the number of requests increased as the moment of death approached, and that a considerable number of patients changed their request to a more 'severe' request, for example a request for euthanasia instead of a request to forgo potentially life-sustaining treatment (Chapter 3).

*Symptoms and EAS*

The high prevalence of symptoms, such as fatigue, feeling unwell, pain, problems with accepting dependency, and deterioration shortly before death, illustrate how illness influences the quality of life of a terminally ill patient and how these health-related problems might contribute to a patient's request for EAS (Chapter 3). It seems that deterioration, in particular, triggers an explicit request for EAS.

*Concerns and EAS*

The patient's concerns seem to play an important role in a request for EAS. One main difference between patients who had requested EAS and patients who had not, seems to be due to high prevalence of concerns in the first group (Chapter 3). Patients inability to cope with the insecurity of the future probably contributes to their hopeless and unbearable suffering, and might

therefore lead to a request for EAS. The suffering of patients who request EAS has been described in some studies as a complex interplay of physical symptoms, psychosocial problems and concerns.[19, 26-28]

*Patients´ reasons*

In contrast to patients who had made a request to forgo treatment, whose main reason for the request was general weakness, patients who had made an explicit request for EAS had done so mainly because of loss of dignity and loss of control over their own life (Chapter 3). The relatives of patients who had died after EAS (Chapter 5) reported that the reasons for patients to request euthanasia were mainly related to hopeless suffering and loss of dignity.

*Terminal care and EAS*

The results of the prospective study focussing on the treatment of symptoms (Chapter 2) indicate that psychosocial symptoms were less often treated than physical symptoms. However, differences in the treatment of physical and psychosocial symptoms were found in both groups of patients, i.e. patients who died after EAS had been performed and patients who did not request EAS (Chapter 4). There were no differences in treatment or care between patients who died after EAS had been performed and patients who did not request EAS. In this study no evidence was found to support the existence of a relationship between (inadequate) terminal care and (a request for) EAS (Chapter 4).

*EAS and end-of-life quality*

According to the relatives of patients who had died after EAS had been performed, hastening the death of the patient mainly contributed to the quality of the end of the patient's life by shortening the suffering (Chapter 5). The relatives thought that by postponing the moment of death the patient's suffering would have been prolonged unnecessarily. The relatives also emphasized the fact that patients found it essential that their last wish should be respected. It is possible that, because they were confident that their last wish would be respected, the patients were less anxious about their future and better able to cope with their concerns, e.g. the hopeless situation and the loss of dignity. The attending physicians also stressed that actively hastening a patient's death might contribute more to the quality of the end of the patient's life than granting a request to forgo a potentially life-sustaining treatment (Chapter 3). The relatives of patients who had died

after EAS had been performed also reported that the dying process of the patient was peaceful and that the patient was usually able to say good-bye (Chapter 5).

### *8.3.3 Physicians´ attitudes and experiences with regard to terminal care and medical end-of-life decisions*

*Physicians´ attitudes to care*

The results of Chapters 6 and 7 describe the attitudes of physicians with regard to terminal care. In the qualitative interviews (Chapter 6) the general practitioners explained that end-of-life care has a 'profound meaning' for them, mainly because of the importance of maintaining the patient's quality of life, lessening the patient's suffering, and supporting a terminally ill patient and the relatives. The general practitioners underlined the significance of their encounters and relationship with the patient and his/her relatives. They indicated that it is essential to be available for terminally ill patients in order to treat their symptoms and to support them at all times. Some of them said that by closing the distance to the patient they were better able to understand and to address the patient's needs (Chapter 6). They stressed the importance of high quality terminal care and of further developments in terminal care (Chapters 6 and 7). Some of them stated that providing high quality terminal care might reduce the need for EAS.

*Deciding about requests for medical end-of-life decisions in general*

The physicians often described EAS as an intervention of last resort, performed when other interventions were no longer able to alleviate the suffering of a terminally ill patient (Chapter 6). They had more ambiguous feelings when deciding about EAS than when deciding about forgoing potentially life-sustaining treatment. Some of them said that they were willing to lessen the unbearable suffering of a patient, but that it could be difficult to face the burden of a decision about EAS (Chapter 3). The irreversible effect of a medical end-of-life decision probably influences the decision-making process, which is in line with our findings that requests for euthanasia were less often granted than requests for forgoing potentially life-sustaining treatment (Chapter 3).

*Dealing with requests for EAS*

The general practitioners reported that dealing with requests for EAS was very demanding (Chapter 6). The way in which they dealt with such a request

was related to several factors, such as the suffering of the patient and their own opinions about palliative care and patient autonomy. Furthermore, their personal values and ability to cope with a request and the performance of euthanasia seemed to be essential. The general practitioners who were interviewed about their experiences indicated they had developed a personal approach to requests for EAS (Chapter 6). Some of them pointed out the importance of the treatment of symptoms in the terminally ill, and the assurance of a peaceful death, and other said that in order to cope with their feeling of powerlessness when treating a terminally ill patient they strove to develop their skills in providing terminal care, which made them more confident about their ability to lessen the patient's suffering. Another group of general practitioners emphasized the importance of making sure that there were no other treatment possibilities before deciding about a request for EAS, and the ability to surpass their own values in order to alleviate the suffering of a terminally ill patient, even if it meant that they would have to perform euthanasia (Chapter 6). Other results (Chapter 3 and Chapter 4) also indicate that the severity of the patient's symptoms was a main factor in the decision-making process concerning a request for EAS.

*Physicians´ attitudes with regard to terminal care and EAS*

The results concerning physicians' attitudes towards terminal care and EAS (Chapter 7) indicate that even though euthanasia is legally regulated in the Netherlands, they were not less cautious about a request for EAS and did not decide more easily about such a request than they did previously (Chapter 6).[29] It is possible, that as a result of the regulation of EAS, more attention is being paid to the development of terminal care. The physicians appeared to appreciate new developments in terminal care and to strive to provide high quality terminal care (Chapter 6 and Chapter 7).

The physician's medical speciality appeared to be related to their opinions about the quality of terminal care (Chapter 7). It is possible that because of their medical experience, they find different specific aspects of terminal care important e.g. for the clinical specialist it is the palliative treatment of illness, for the nursing home physicians it is care for the elderly, and for general practitioners it is availability for a terminally ill patient and his/her family members.

**8.4 Conclusions**

Terminally ill patients suffer increasing 'distress, related to physical and psychosocial symptoms and concerns, during the final period of their life.

Physical symptoms are treated more often than psychosocial symptoms. However, a request for EAS from a terminally patient does not appear to be based on inadequate treatment of symptoms or inadequate care.

The high prevalence of concerns, mainly related to symptoms such as pain, dyspnoea, ADL-dependency and also loos of dignity, indicate that terminally ill patients are confronted with uncertainty and apprehension. The number of concerns is also related to the patient's psychosocial well-being and symptoms such as coping problems, depressive feelings, or feelings of powerlessness. Concerns seem to be an important element of a patient's unbearable and hopeless suffering.

Requests for EAS develop over quite a long period of time, and appear to be related to the way in which patients appraise their own ability to cope with the consequences of illness at the end of their life. In addition to the severity of the deterioration e.g. increase in the severity and number of symptoms, the patients personal perception of controlling their own life and death and maintaining dignity, are factors that are related to the development of an explicit request for EAS.

Physicians are more reluctant to grant a request for EAS than a request to forgo potentially life-prolonging treatment. The physician's EAS decision-making process is based mainly on the consequences? of EAS on the quality and duration of the end of life, further treatment possibilities, the physician's own values and experiences, and expertise in handling a request and performing euthanasia. However, the severity of symptoms appears to be a major criterion in granting a request for EAS.

## 8.5 Implications of the results

The results of the studies described in this thesis can stimulate developments concerning policy, the practical aspect of caring for terminally ill patients, and further studies focusing on terminal care and medical end-of-life decisions. Some implications of the findings in relation to these area will be described below.

### *8.5.1 Implications with regard to policy and practice*

*Developing physician's skills in terminal care*

The fact that physicians, and especially general practitioners, indicate that they often feel powerless when treating a terminally ill patient (Chapter 6), should lead to an intensification of the efforts directed at increasing the abilities of physicians to treat symptoms and to care for terminally ill patients and their relatives. This could be achieved through formal education, post-academic training, consultation with experts, and the development of treatment guidelines based on scientific evidence. It is essential to train physicians to address the suffering of such patients and the various aspects that are related to it. Directing physicians' attention not only to clinical aspects, but also to more subjective aspects related to a terminal illness, such as the patient's experience and psychosocial and relational needs, would probably help physicians in developing a comprehensive approach to the suffering of a terminally ill patient. In addition to alleviating the suffering caused by symptoms, it might be important that physicians strive to find a way to value and empower the terminally ill patient, e.g. by identifying the patient's unique priorities, in order to promote the patient's end-of-life quality.[26, 30-32]

In order to support physicians in addressing the concerns of such patients, it might be essential to train their communication skills. The quality of communication between a care-giver and a patient has often been described as an essential aspect of terminal care.[19,31] The enhancement of physicians´ skills in providing terminal care should be achieved through further development of the medical curriculum. Furthermore, professional physicians organizations could develop a policy directed at encouraging ongoing education and the development of further skills in providing terminal care, particularly for physicians who regularly treat terminally ill patients.

*Offering emotional support to physicians*

It might also be important to offer emotional support to physicians in order to help them to cope with the burden related to terminal care and medical end-of-life decisions, and in particular EAS. When deciding about a request for EAS, physicians do not only need support to establish the rational of their decision, for example to meet the requirements for prudent practice, but also to be able to describe their experience of dealing with a request for EAS and the way in which they intend to respond to a request. Emotional support should also be available for physicians after that they have performed EAS. This should help to lessen the burden associated with (the decision-making process concerning) EAS.

Encouraging physicians to plan a timely discussion with a colleague about a request for EAS from a terminally ill patient might help the physician to cope with the request, subsequently to discuss it with the patient and the relatives, and finally to make a decision.

Medical associations, such as the Royal Dutch Medical Association (KNMG), might stimulate physicians to consult a colleague and to discuss their views regarding a request for EAS. Furthermore, it should be investigated whether, within the national programme of Support and Consultation on Euthanasia in the Netherlands (SCEN), it is feasible not only to offer a formal consultation or practical advice to physicians who are confronted with a request for EAS (judging whether all the requirements for prudent practice are met), but also to pay systematic attention to the experiences of physicians and to the possible emotional aspects related to the decision-making process concerning a request for EAS.

*Shaping a realistic image of terminal care and medical end-of-life decisions*

Information about medical end-of-life decisions and EAS that is provided to the general public should clearly explain that deciding about a request might take some time, because specific requirements for prudent practice have to be respected by the physician, and also because of the personal involvement of the physician in such a serious decision. Patients should therefore be encouraged to speak to their attending physician as early as possible about their own wishes with regard to medical end-of-life decisions.

The decision-making process concerning a request for EAS need not

be reduced to a ´technical´ process, but should still be approached as a complex and dynamic process affecting the physician personally as well as aspects of his private life, including his own history and development. Therefore, the information given to patients and the general public should not present a simplified image of EAS as a patient's right that must always be honoured when (certain) criteria are met. The information should clearly explain that EAS is an aspect of terminal care, and is related to several illness factors such as the patient's suffering. As the study results indicate that a request for EAS develops over a long period of time and that dealing with a request for EAS is very demanding, it is essential to emphasize that deciding about a request for EAS has to take place within the context of the relationship between the attending physician and the patient. Presenting terminal care and EAS as two opposite poles might lead to erroneous ideas about terminal care, e.g. mainly directed at preventing requests for euthanasia or ignoring a patient's request for EAS. It might be more fruitful, irrespective of opinions about the acceptability of EAS, to describe medical end-of-life decisions, and thus also EAS, as an integral but exceptional aspect of terminal care. Furthermore, because there is a lack of nuances in descriptions of medical end-of-life decisions that regularly appear in the media, this often make the public suspicious of health care providers, and this has a negative influence on the relationship between the patient, the patient's relatives and the physician. The Ministry of Health and the medical professional associations should therefore make joint efforts at shaping a realistic image of terminal care and EAS. In this direction an initiative has already been taken to clearly describe significant concepts related to terminal care.[33] Medical professional associations should strive to promptly rectify erroneous information distributed by the media.

*Development of terminal care*

Symptoms and concerns are important aspects of the suffering of patients. The high prevalence of some symptoms indicates that efforts to treat symptoms must continue, mainly those symptoms that could might be prevented or easily treated, such as pressure ulcers and a dry mouth.

This thesis indicates that in order to address a patient's suffering at the end of life it might be essential to pay adequate attention to the patient's concerns and psychosocial problems.

Compared with the treatment of physical symptoms, it is often difficult to determine which aspects of a clinical intervention or approach are the most effective in addressing such problems. However, it is essential to develop and to adopt care approaches directed at supporting the psychosocial well-being of a terminally ill patient. Having enough time to develop a relationship with the patient should enhance the patient's confidence and ability to express his/her own concerns, and make it possible for care-givers to gain more insight into the suffering of the patient.

Finally, as relatives might be an essential source of well-being and comfort for a terminally ill patient, it is important to facilitate their involvement in supporting and caring for the patient. Consequently, health care must be organized in such a way that meeting loved ones and sharing (enough) time with them is still easy and possible. It is the responsibility of the individual health care provider to develop good quality terminal care in such a way that the needs of the patients and their relatives are met in the most effective way.

The results of this thesis indicate that the psychosocial needs and problems of a terminally ill patient might have an important influence on the patient's experience and end-of-life quality, as well as on the patient's wishes concerning medical end-of-life decisions. In order to address the needs and wishes of a terminally ill patient with regard to terminal care and medical end-of-life decisions it is essential to gain insight into aspects related to the patient's well-being in an earlier phase of the illness.

Instead of an approach to the patient that focuses mainly on health-problems, a more comprehensive approach based on personalized care values and including compassion and emotional support, should be adopted in order to gain insight into the patient's needs and wishes with regard to the end-of-life in an earlier phase of the illness.[30,37,38]

Professionals and researchers must encourage the dissemination and utilization of study results in order to improve the quality of care. Recent developments, such as the development of directives for palliative care [39] and of directives for palliative sedation,[40] show how evidence based on study results and expert knowledge could contribute to improvement in the practical aspect of terminal care. Professionals and researchers should regularly pool their efforts in order to assess how (some aspects of) care for the terminally ill could be developed

and how strong evidence and increased insight might contribute to the improving quality of terminal care.

*Feeling of dignity*

Patients, and especially those who (might) request EAS, seem to have specific ideas and expectations about the quality of their life, about what they are prepared to accept or not, and about maintaining a feeling of dignity. They probably feel threatened by possible consequences of the illness and by certain types of medical treatment. Therefore, it might be essential to them to feel supported in maintaining a feeling of dignity, and by paying explicit attention to such concerns early during the illness process, e.g. by encouraging them to express their thoughts and wishes, caregivers will probably enhance the patient's trust with regard to this essential issue.[34]

### *8.5.2 Implications with regard to further research*

*Dying process*

More insight has been provided into the dying process and various aspects related to a peaceful death (Chapter 2). However, the needs and expectations of terminally ill patients with regard concern to their death have not yet been adequately addressed. Dying is a very personal process, influenced by personal history and culture.[2,35] In order to personalize the support and care that is provided it is necessary to gain systematic insight into a patient's needs and expectations with regard to the dying process, and the way in which these needs are expressed. The necessary insight could be obtained in a qualitative approach, based on open interviews and participant observation. The results of such research might provide support for caregivers in eliciting a patient's needs with regard to the dying process and addressing them (more) adequately.

*Developments of requests for euthanasia*

Psychosocial problems are often related to requests for EAS.[36] In addition to describing illness-related problems and reasons why terminally ill patients request EAS, it might also be meaningful to determine whether and how some specific factors, such as loss of dignity, concerns, feelings of hopelessness, and also (loss of) relationship with others and social function, are related to requests for EAS.[36]

It is furthermore important to gain insight into the mechanisms by which some aspects related to the physician-

patient relationship, such as communication and the physician's opinion about EAS, affect the development and the expression of a terminally ill patient's request for EAS.
A prospective follow-up study design, including regular qualitative interviews with terminally ill patients about their illness experiences and quality of life during the final month of their life, will provide more insight into the background and development of a request for EAS and certain related factors, such as loss of dignity, feelings of powerlessness, and experience of deterioration. Such a study might also provide more insight into about the way in which patients strive to cope with the losses related to terminal illness and to maintain end-of-life quality.

*Experiences of physicians*

Dealing with and deciding about a request for EAS can be very demanding. Studies investigating physicians' experiences and addressing their needs with regard to emotional support might lead to develop specific programs directed at supporting physicians. Insights concerning the way in which they cope with EAS should be used to develop questionnaires that could be used in large scale studies about physicians' experiences and needs with concern to terminal care and requests for EAS.

The participation of large numbers of physicians and of relatives of patients in this study in particular and in other studies about medical end-of-life decisions in the Netherlands make it possible to gain more insight in this important area and also clearly indicate that physicians and relatives are prepared to invest time in developing terminal care further.

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# Summary

## Medical end-of-life decisions in the context of terminal care

*The study*

A prolonged life-expectancy, the increasing burden caused by chronic illnesses, the pattern of death changing from a sudden, acute episode to a longer process of dying accompanied by physical and mental deterioration, have lead to an increase in the attention that is paid to improving the quality of the end-of-life of patients.

The objectives of the present study were to gain more insight into medical end-of-life decisions, especially euthanasia and physician-assisted suicide (EAS), within the context of terminal care.

The following research questions were addressed:

1. What are the (health) problems that terminally ill (cancer) patients encounter during the final months of their life, and how are they treated and cared for?
2. Which wishes related to medical end-of-life decisions, and more specifically with regard to euthanasia and physician-assisted suicide do terminally ill (cancer) patients have? Which factors are related to the development of these wishes?
3. What are physicians´ attitudes and experiences with regard to terminal care and medical end-of-life decisions, especially concerning euthanasia and physician-assisted suicide?

In order to address these research questions several studies were performed:

A physician interview study among a random sample of general practitioners (n=125), nursing home physicians (n=77), and clinical specialists (n=208). Physicians were retrospectively interviewed in 2001 by trained physicians about their experiences with regard to requests for EAS from terminally ill (cancer) patients and terminal care. The results of this study are described in Chapters 4 and 7.

A prospective study based on a questionnaire that was filled by the attending physicians of terminally ill cancer patients (n= 85) to describe the patients' symptoms and concerns, the treatment of the symptoms, and the care provided for the patient, the patients´ requests concerning medical end-of-life decisions, and the attending physician's decision with regard to the patient's request. The results of this study are mainly described in Chapters 2 and 3.

A study based on interviews with relatives of patients who died after their request for EAS had been granted (n=87). The aim of this study was to assess the experience of the terminally ill patient and the way in which EAS had contributed to the quality of the end of the patient's life. The results of this study are described in Chapter 5.

A qualitative study based on interviews with general practitioners (n=31) about their experiences and attitudes with regard to terminal care and EAS. The results of this study are described in Chapter 6.

A study based on questionnaires to investigate the experiences and opinions of the members of the Euthanasia Review Committees (ERCs)(n= 35) concerning terminal care and EAS. The results of this study are described in Chapter 7.

## *Results*

*Health problems and care in terminally ill cancer patients*

Terminally ill cancer patients are confronted with an increasing number of symptoms during the final months of their life (Chapter 2). The most prevalent symptoms in our study population of 85 terminally ill cancer patients some one to two months before their death were fatigue, loss of appetite, ADL-dependency and feeling unwell. Shortly before death there was an increase in the prevalence of these symptoms and of other disturbing symptoms such as pressure ulcers, problems with swallowing, a dry mouth, and incontinence. There was also an increase in the average number of physical symptoms shortly before death. The psychosocial well-being of most patients was, above all, hampered by problems with coping, powerlessness, anxiety, and problems with accepting dependency. Confusion and a diminished level of consciousness, which are potentially related to physiological processes, worsened with the approach of death, but psychosocial problems related to mood, such as coping problems, anxiety and powerlessness improved or stabilized shortly before death. The patients also had many concerns during the final months of their life. These were, above all, related to symptoms such as pain and dyspnoea, ADL-dependency and loss of dignity (Chapter 3 and Chapter 5). Patient concerns were related to a wide range of psychosocial symptoms, e.g. problems with coping, depressive feelings, feelings of powerlessness and feelings of meaninglessness (Chapter 3). These concerns seem to be an important aspect of the unbearable

suffering of patients with a terminal illness.

According to their physicians, the majority of patients died peacefully (73%)(Chapter 2). The average number of psychosocial symptoms and some specific symptoms, e.g. anxiety, loneliness and meaninglessness, had a negative effect on the dying process, while being cared for by loved ones, having said good-bye and being ready to die were positively correlated with dying peacefully.

With regard to terminal care, the results of the prospective study (Chapter 2) showed that physical symptoms, and especially pain, were treated much more often than psychosocial problems. Only a few patients were treated for depression, anxiety and confusion at the moment of inclusion, but shortly before death more attention was paid to these problems, especially when they were rated as severe.

*Terminally ill patients' requests with regard to medical end-of-life decisions*

The patients' explicit request for EAS generally developed over a longer period of time, and explicit requests for EAS were generally made late in the illness. Most patients had already expressed their wish with regard to medical end-of-life decisions, and in favour of EAS under specific conditions before they became terminally ill (Chapter 5). Before they became terminally ill, the patients were above all concerned about loosing their dignity, becoming ADL-dependent, having pain and becoming a burden (Chapter 3).

Compared with requests for forgoing life-sustaining treatment, requests for EAS were made for a greater number of reasons, the most frequent of which were general weakness, hopeless suffering, and loss of dignity. Loss of dignity was significantly more often a reason to request EAS than a reason to make a request to forgo a potentially life-sustaining treatment (Chapter 3). Loss of dignity and hopeless suffering were the most important reasons for which patients requested EAS (Chapter 3 and Chapter 5). The prevalence of fatigue, dependency, feeling unwell and psychosocial problems was higher in patients who had requested EAS than in patients who had made a request to forgo a potentially life-sustaining treatment. The increase in the number of (severe) symptoms and concerns during the final months of life was especially important in patients who requested EAS. It seems that especially physical suffering accompanied by psychosocial problems and concerns lead to a request for EAS (Chapter 3).

Terminally ill cancer patients who died after their EAS had been performed suffered from more (severe) symptoms such as pain, vomiting, nausea, coughing and feeling unwell, than patients who had not requested EAS (Chapter 4). In both groups the symptoms were treated with the same frequency, but physical symptoms were treated more often than psychosocial symptoms, and in both groups the care that was provided was considered to be adequate by the attending physician. These study results indicate that the development of a request for EAS does not result from inadequate care, but mainly from the suffering of the patient.

The relatives of terminally ill patients who died after EAS had been performed reported that EAS mainly contributed to the quality of the end of the patient's life by shortening the suffering and also because the patient's last wish had been granted. According to the relatives, the majority of patients who died after EAS were ready to die, had said good-bye to their loved ones before they died, and had died peacefully (Chapter 5).

*Physicians' attitudes and experiences with regard to terminal care and medical end-of-life decisions*

Most physicians stressed the importance of high quality terminal care and of further developments in terminal care (Chapter 6 and Chapter 7). Some of them stated that high quality terminal care might lessen the need for patients to request EAS.

Physicians often described EAS as an intervention of last resort, performed when other interventions were no longer able to alleviate the suffering of a terminally ill patient (Chapter 6). They seemed to have more ambiguous feelings when deciding about EAS than when deciding about forgoing a potentially life-sustaining treatment. The results also indicate that the severity of the patients´ symptoms was a major aspect in the decision-making process concerning a request for EAS (Chapter 3 and Chapter 4).

The general practitioners reported that they felt satisfied that they could shorten the unbearable suffering of a patient, but that it could be difficult to face the burden of a decision about EAS (Chapter 3 and Chapter 6).

In their opinion, dealing with requests for EAS was very demanding (Chapter 6). The way in which they dealt with a request for euthanasia was related to several factors such as the suffering of

the patient and their own personal opinion about palliative care and patient autonomy. Furthermore, the physicians' personal values and ability to cope with a request and with the performance of euthanasia seemed to be essential. Some general practitioners emphasized the importance of the treatment of symptoms in the terminally ill and of assuring the patient a peaceful death, and others emphasized the importance of developing their skills in providing terminal care in order to be better able to lessen the patient's suffering. Some physicians said that when no other treatment was possible they had to be able to surpass their own values in order to alleviate the suffering of a terminally ill patient, even if it meant that they would have to perform euthanasia (Chapter 6).

In the Netherlands, where EAS is legally regulated and openly discussed, physicians appear to have a balanced opinion with regard to EAS. However, even if they believe that terminal care can be improved, they do not seem to be convinced that terminal care can always sufficiently alleviate all suffering at the end of life. Most of them are therefore of the opinion that euthanasia can be appropriate in some cases (Chapter 7).

# Samenvatting

## Medische beslissingen aan het einde van het leven in de context van terminale zorg.

*Het onderzoek*

De steeds langere levensverwachtingen, de belasting van chronische ziektes waarvoor genezing niet meer mogelijk is, en de toename van langere stervensprocessen zijn enkele ontwikkelingen die geleid hebben tot meer aandacht voor de terminale zorg en medische beslissingen rond het levenseinde bij terminale patiënten.

Het doel van deze these is erop gericht meer inzicht te krijgen in medische beslissingen rond het levenseinde, in het bijzonder tot euthanasie and hulp bij zelfdoding (EHBZ), in het perspectief van terminale zorg.

De volgende vragen zijn geformuleerd:

1. Welke zijn de gezondheidsproblemen van terminale zieke (kanker) patiënten, tijdens de laatste maanden van hun leven, en hoe worden ze behandeld en verzorgd?
2. Welke wensen gerelateerd aan medische beslissingen rond het levenseinde, en in het bijzonder gerelateerd aan EHBZ hebben terminale zieke (kanker) patiënten? Welke factoren zijn gerelateerd aan de ontwikkeling van deze wensen?
3. Wat is de houding en de ervaring van artsen ten opzichte van terminale zorg en ten opzichte van verzoeken tot een medische beslissing rond het levenseinde, in het bijzonder ten opzichte van EHBZ?

Om in te gaan op deze onderzoeksvragen zijn er verschillende onderzoeken verricht:

Een onderzoek gebaseerd op interviews met een aselecte steekproef van huisartsen (n=125), verpleeghuisartsen (n= 77) en klinische specialisten (n= 208). De artsen werden in het jaar 2001 geïnterviewd door getrainde artsen over hun ervaring met betrekking tot verzoeken tot EHBZ van terminale zieke (kanker) patiënten en de zorg aan het einde van het leven. De resultaten van dit onderzoek zijn beschreven in de hoofdstukken 4 en 7.

Een prospectief onderzoek waarbij vragenlijsten die ingevuld werden door de behandelende arts van een terminale zieke (kanker) patiënt. Dit onderzoek was gericht op het beschrijven van de symptomen en zorgen, de behandeling van de symptomen en de zorg aan de patiënt, de verzoeken van de patiënt ten opzichte van medische beslissingen rond het levenseinde en de beslissing van de behandelende artsen over het

verzoek van de patiënt. De resultaten van dit onderzoek zijn voornamelijk beschreven in de hoofdstukken 2 en 3.

Een onderzoek gebaseerd op interviews met familieleden van patiënten die overleden zijn nadat hun verzoek tot euthanasie ingewilligd werd (n=87). Het doel van dit onderzoek was om inzicht te verkrijgen in de ervaring van de terminaal zieke patiënten en in de wijze waarop EHBZ had bijgedragen aan de kwaliteit van het einde van hun leven. De resultaten van dit onderzoek zijn beschreven in hoofdstuk 5

Een kwalitatief onderzoek waarbij interviews met huisartsen (n=31) zijn gehouden over hun houding en ervaring ten opzichte van de zorg aan terminale zieke patiënten en ten opzichte van EHBZ. De resultaten van dit onderzoek zijn beschreven in hoofdstuk 6.

Een onderzoek waarbij vragenlijsten zijn gebruikt om de ervaring en mening van leden van de regionale toetsingscommissies euthanasie (RTC) (n=35) ten opzichte van terminale zorg en EHBZ te beschrijven. De resultaten van dit onderzoek zijn beschreven in hoofdstuk 7.

## ***Resultaten***

De belangrijkste resultaten van de onderzoeken worden beschreven in overeenstemming met de onderzoeksvragen van deze these.

### *Gezondheidsproblemen van terminale zieke patiënten en terminale zorg*

De resultaten beschreven in hoofdstuk 2 met betrekking tot de gezondheidsproblemen van terminale zieke kanker patiënten wijzen erop dat patiënten te maken hebben met een toenemend aantal symptomen tijdens de laatste maanden van hun leven. De meest voorkomende symptomen in deze studie populatie van 85 terminale zieke kanker patiënten, ongeveer twee maanden voor hun overlijden, waren vermoeidheid, verlies van eetlust, afhankelijkheid voor dagelijkse activiteiten en zich slecht voelen. Kort voor het overlijden was de prevalentie van deze symptomen en van andere storende symptomen zoals decubitus, slikproblemen, droge mond en incontinentie en het gemiddeld aantal fysieke symptomen toegenomen.

Het psychosociale welzijn van de meeste patiënten was voornamelijk verstoord door verwerkingsproblemen, machteloosheid, angst en moeilijkheden om de afhankelijkheid te accepteren. Klachten zoals verwardheid en verlaagd bewustzijn, die vooral gerelateerd zijn aan fysiologische processen, werden erger kort voor het overlijden.

Psychosociale problemen die vooral aan de stemming van de patiënt gerelateerd zijn zoals problemen om te verwerken, angst en machteloosheid, verbeterden of bleven stabiel kort voor het overlijden van de patiënt.

Patiënten hadden ook een groot aantal zorgen tijdens de laatste maanden van hun leven. Ze waren vooral bezorgd om bepaalde symptomen zoals pijn en dyspnoe, ADL-afhankelijkheid en het verlies van hun gevoel van waardigheid (hoofdstuk 3 & hoofdstuk 5). De resultaten wijzen er verder op dat de zorgen van patiënten te maken hadden met een groot aantal psychosociale symptomen zoals verwerkingsproblemen, gevoelens van depressiviteit, gevoelens van machteloosheid en zingevingproblemen. Het is daardoor waarschijnlijk dat de zorgen van patiënten een belangrijk element van het ondraaglijk lijden zijn bij terminale patiënten.

De resultaten van dit onderzoek wijzen erop dat de meerderheid van de patiënten, volgens hun behandelende arts, rustig overleden (73%) (hoofdstuk 2). Verdere analyse van de gegevens maakte duidelijk dat het gemiddeld aantal psychosociale symptomen en sommige specifieke symptomen zoals angst, eenzaamheid en zingevingproblemen een negatieve invloed hadden op het overlijdensproces. Aan de andere kant, verzorgd worden door een naast familielid of vriend, afscheid hebben genomen en klaar zijn om te overlijden werden positief gecorreleerd met rustig /vredig overlijden.

De resultaten met betrekking tot terminale zorg in het prospectief onderzoek (hoofdstuk 2) brengen naar voren dat fysieke symptomen, in het bijzonder pijn, vaker behandeld werden dan psychosociale symptomen. Alleen enkele patiënten werden behandeld voor hun depressieve gevoelens, voor angst en voor verwardheid op het moment van de inclusie. Kort voor het overlijden werd er meer aandacht aan deze problemen geschonken vooral wanneer ze als 'ernstig' beschouwd werden.

*Verzoeken van terminale zieke patiënten ten opzichte van medische beslissingen rond het levenseinde*

Vergeleken met verzoeken tot het afzien van een mogelijk levensverlengende behandeling waren verzoeken tot EHBZ gerelateerd aan een groter aantal redenen. Van deze redenen kwamen algehele zwakte, uitzichtloos lijden en verlies van waardigheid het meest naar voren. Verlies van waardigheid werd beduidend vaker als reden voor een verzoek tot EHBZ genoemd dan als reden voor een verzoek tot het afzien van een levensverlengende behandeling

(hoofdstuk 3). Verlies van waardigheid en uitzichtloos lijden waren de belangrijkste redenen voor verzoeken tot EHBZ (hoofdstuk 3 & hoofdstuk 5).

Met betrekking tot de symptomen bij patiënten met een verzoek tot EHBZ, was de prevalentie van vermoeidheid, afhankelijkheid en zich slecht voelen, en van psychosociale problemen hoger dan bij patiënten die een verzoek tot het afzien van een levensverlengende behandeling hadden. De toename van (ernstige) symptomen en zorgen van patiënten was vooral aanzienlijk bij patiënten die een verzoek tot EHBZ hadden gedaan.

De resultaten beschreven in hoofdstuk 5 laten zien dat de meeste patiënten hun wens voor EHBZ in specifieke omstandigheden al hadden uitgesproken voordat ze terminaal ziek waren. Voordat ze terminaal ziek waren, waren patiënten vooral bezorgd om het verlies van hun gevoel van waardigheid, ADL-afhankelijk te worden, pijn te hebben en een belasting voor anderen te worden.

Het gevoel van waardigheid bleek een kern element van de ervaring van het ziek zijn en in belangrijke mate bij te dragen aan het tot stand komen van verzoeken tot EHBZ. Het lijkt erop dat lijden veroorzaakt door problemen van fysieke aard samen met psychosociale problemen en zorgen vooral tot verzoeken voor EHBZ leidt (hoofdstuk 3)

*Factoren gerelateerd aan EHBZ*

De resultaten van het onderzoek waarbij terminale zieke kanker patiënten die overleden zijn nadat hun verzoek tot EHBZ werd uitgevoerd vergeleken zijn met patiënten die geen verzoeken tot EHBZ hadden geuit, wijzen erop dat de eerste groep patiënten aan meer (ernstige) symptomen zoals pijn, overgeven, misselijkheid, hoesten en zich slecht voelen, lijden dan de patiënten die geen verzoek tot EHBZ hadden gedaan (hoofdstuk 4).

Voor wat betreft de behandeling van symptomen werd er in beide groepen een vergelijkbaar patroon in de frequentie van de behandelingen beschreven. Fysieke symptomen werden vaker behandeld dan de psychosociale symptomen. In beide groepen werd de zorg die aan een patiënt verleend was als adequaat beoordeeld door de behandelend arts. De resultaten van dit onderzoek wijzen erop dat het ontwikkelen van een verzoek tot EHBZ niet het gevolg is van inadequate zorg, maar vooral het gevolg is van het lijden van de patiënt.

Familieleden die het meest betrokken waren bij de zorg van een terminaal zieke patiënt die overleden is nadat EHBZ was uitgevoerd beschreven dat

EHBZ vooral aan de kwaliteit van het einde van het leven van de patiënt bijgedragen heeft door het verlichten en beëindigen van het lijden van de patiënt en ook omdat op deze wijze de laatste wens van de patiënt gerespecteerd werd.

De meerderheid van de patiënten die overleden zijn nadat hun verzoek tot EHBZ uitgevoerd werd waren klaar om te overlijden en hadden afscheid genomen van hun naasten voordat ze overleden. Volgens familieleden zijn alle patiënten vredig overleden (hoofdstuk 5).

*Houding en ervaring van artsen ten opzichte van de terminale zorg en medische beslissingen rond het levenseinde*

Artsen bleken minder bereid om een verzoek tot EHBZ in te willigen dan een verzoek tot het afzien van een levensverlengende behandeling.

Doelbewust bespoedigen van het levenseinde wordt, in tegenstelling met het afzien van een levensverlengende behandeling, gezien als een bijzondere medische handeling (hoofdstuk 3 & hoofdstuk 6). De aanwezigheid van ernstige symptomen blijkt essentieel te zijn voor artsen om een verzoek tot EHBZ in te willigen (hoofdstuk 3).

Geconfronteerd worden met een verzoek tot EHBZ van een terminale zieke patiënt wordt door de arts die erop gericht is het lijden van de patiënt te verminderen, als een veeleisende ervaring beschreven (hoofdstuk 6).

Artsen proberen een evenwicht te vinden tussen hun eigen waarden en de noodzaak om het lijden van een patiënt te verminderen en euthanasie te moeten uitvoeren. De attitude van huisartsen ten aanzien van verzoeken tot euthanasie was vooral gerelateerd aan hun mening en gevoelens over (het uitvoeren van) euthanasie, hun mening ten opzichte van de relatie tussen palliatieve zorg en euthanasie en hun houding ten opzichte van de voorkeuren van patiënten met betrekking tot medische beslissingen rond het levenseinde. Sommige huisartsen trachten te vermijden het levenseinde van een patiënt op zijn verzoek doelbewust te moeten bespoedigen, omdat ze euthanasie afkeurden. Ze trachtten zich dan ook vooral te richtten op het verminderen van de gevolgen van ondraaglijke symptomen die het stervensproces verergerden. Andere huisartsen waren er vooral op gericht de kwaliteit van het levenseinde van een patiënt te bevorderen door zorg en steun aan de patiënt en aan zijn naasten in de plaats van euthanasie te moeten verrichten. Een derde groep huisartsen trachtte open te staan voor verzoeken tot euthanasie. Zij probeerden op gevoelige en open wijze om te gaan met

verzoeken tot euthanasie en om een evenwicht te vinden tussen de noodzaak om het lijden te verminderen en EHBZ uit te voeren en hun eigen waarden.

In Nederland waar EHBZ wettelijk geregeld is en openlijk besproken, blijken artsen een afgewogen mening te hebben over EHBZ. Desondanks, ook als ze in het verder ontwikkelen van terminale zorg geloven, blijken ze niet ervan overtuigd te zijn dat het lijden van een patiënt ten alle tijde verlicht kan worden door middel van zorg en denken dat in sommige gevallen euthanasie geschikt zou kunnen zijn (hoofdstuk 7).

# Résumé


## Décisions médicales en fin de vie dans le contexte de soins terminaux

*La recherche*

Le prolongement de l´ espérance de vie, les conséquences des maladies chroniques pour lesquelles aucun traitement curative n' existe, la diminution du nombre de décès inattendues, sont des facteurs qui ont contribués au développement des soins de fin de vie et a un accroissement de prise de décisions médicales relatées à la fin de vie auprès de patients atteints de maladie terminales.

Les décisions médicales en fin de vie et en particulier les décisions qui on pour conséquence de diminuer consciemment la durée de fin de vie auprès de patients terminaux tel que l' euthanasie et le suicide assisté médicalement (ESA) forment l'objet de nombreuses discussions. Diverses opinions on été émises à ce sujet, comme par exemple que la qualité des soins en fin de vie pouvait avoir comme conséquence qu' une demande pour ESA ne soit pas nécessaire ou même qu'une demande pour ESA soit par cela empêchée.

Cependant l' euthanasie et le suicide assisté médicalement sont aussi parfois décrits comme des moyens pouvant assurer ou contribuer à terminer une période de soins palliatifs de haute qualité pour un patient en phase terminale de manière digne.

Jusqu' ā présent peu d' études scientifiques destinées à décrire plus clairement la relation entre les soins de fin de vie et l'euthanasie ont été réalisées.

Cette thèse a pour but d' élargir notre regard sur le sujet des décisions médicale prises en phase terminale de maladie. Les différentes questions de recherche on été dirigées sur la description des problèmes de santé de patients en phase terminale, les soins à ces patients, les demandes de patients concernant les décisions médicales de fin de vie, et les décisions des médecins à propos de ces demandes et plus particulièrement en ce qui concerne l'euthanasie et le suicide assisté médicalement.

Les questions de recherche ont été formulées de la manière suivante:

1. Quels sont les problèmes de santé de patients incurables durant les derniers mois de leurs vie, comment sont t-ils traitées et soignés ?
2. Quels sont les souhaits de patients incurables concernant les décisions médicales en fin de vie, et plus particulièrement l' euthanasie et le

suicide assisté médicalement? Quels sont les facteurs liés au développement de ces souhaits ?

3. Quelles sont les positions et expériences des médecins concernant les soins de fin de vie et les décisions médicales en fin de vie, et plus particulièrement en ce qui concerne l'euthanasie et le suicide assisté médicalement?

Afin d' adresser ces questions différentes études ont été entreprises:

Une étude basée sur des interviews avec des médecins de famille (n= 125), médecins de maisons de soins (n= 77), et spécialistes clinique (n= 208).

Ces médecins on été interviewés à propos de leur expérience concernant des demandes pour ESA et concernant les soins terminaux en 2001, par des médecins formés pour ce propos. Les résultats de cette recherche sont décrits dans les chapitres 4 et 7

Une étude prospective dirigée à décrirent l´évolution de symptômes, des préoccupations et des demandes de patients souffrant d´une forme incurable de cancer (n= 85) concernant leurs traitements médicaux de fin de vie et les demandes pour euthanasie et suicide assisté médicalement. Les résultats de cette recherche sont décrits dans le chapitre 2 et le chapitre 3.

Une recherche auprès de proches de patient décédés après que leur demande pour ESA a été agréée (n= 87). Le but de cette recherche était principalement de pouvoir décrire l´expérience de fin de vie de patients en phase terminale en relation avec l'euthanasie et le suicide assisté médicalement. Les résultats de cette recherche sont présentés dans le chapitre 5.

Une recherche qualitative, dirigée à décrire l´expérience de médecins de famille en ce qui concerne les soins de fin de vie et les demandes pour ESA. (n= 31). Les résultats de cette recherche sont présentés dans le chapitre 6.

Une recherche à base de questionnaires dirigés à décrire l´opinion et l´expérience des membres des commissions de revue de cas d´euthanasie et de suicide assistées (n= 35). Les résultats de cette recherche sont décrits dans le chapitre 7.

## *Résultats*

Ci-dessous les résultats principaux sont décrits conformément aux différentes questions de recherche.

*Problèmes de santé de patients et soins terminaux.*

Les résultats concernant les problèmes de santé en phase terminale de cancer décrits dans le chapitre 2 montrent que

les patients sont confrontés à un nombre croissant de symptômes durant les derniers mois de leur vie. Deux mois avant leur décès les patients souffraient surtout de symptômes tel que la fatigue, la perte d'appétit, être dépendant pour les activités quotidiennes, et se sentir mal. Peu de temps avant leurs décès la prévalence de ces symptômes et d'autres symptômes comme des plaies de decubitus, des problèmes de déglutition, une bouche sèche, et des problèmes de continence, ainsi que le nombre moyen de symptômes étaient augmenté.

Le bien-être psychosocial du patient était surtout affecté par des difficultés à accepter la maladie et la dépendance, par des sentiments d´impuissance et d´anxiété. Des états de confusion et de diminution du niveau de conscience semblaient s´aggraver à l´approche du moment du décès. Alors que des problèmes psychosociaux, surtout causées par des changements d´humeur, tel que des sentiments d´anxiété et d´ impuissance, semblaient devenir moins grave à l'approche de la mort.

Les patients avaient aussi beaucoup de soucis et de préoccupations durant les derniers mois de leur vie. Ces soucis étaient surtout liés aux symptômes, tel qu´ à la douleur, l´essoufflement, la dépendance et aussi la perte de dignité. Les soucis des patients étaient aussi liés à un grand nombre de problèmes psychosociaux tel que les problèmes d´acceptation, des sentiments dépressifs, des sentiments d´impuissance et à des difficultés a trouver un sens à la vie (Chapitre 3). Ces soucis semblaient expliquer en partie le sentiment de souffrance insupportable qu´éprouvaient ces patients.

D´après les médecin traitant la majorité des patients étaient décédé paisiblement (73%) (Chapitre 2).

Les facteurs expliquant une mort paisible étaient la présence de proches, avoir pu faire ces adieux et se sentir prêt à faire face à sa mort.

En ce qui concerne le traitement des symptômes, les soins/traitements médicaux étaient plus souvent dirigés sur les symptômes physiques que sur les symptômes psychosociaux, bien que ces symptômes, et surtout la dépression et l´anxiété, étaient traités plus fréquemment peu avant le décès du patient (Chapitre 2).

*Souhaits et demandes des patients concernant les décisions médicales de fin de vie*

Les demandes d´euthanasie et de suicide assisté médicalement se développent durant une période plus ou moins longue. Ces demandes sont

exprimées de manière explicite beaucoup plus tard durant la maladie. La majorité des patients avait exprimés ses souhaits concernant les décisions médicales en fin de vie avant d´être gravement malade (Chapitre 5). Les patients semblaient alors déjà fortement préoccupés par les menaces de perte de dignité, de la douleur et se sentir un fardeau pour leurs proches (Chapitre 3).

Les demandes explicites pour euthanasie ou suicide assisté étaient basées sur un plus grand nombre de raisons que les demandes d´arrêt d´un traitement médicale susceptible de prolonger la vie. Les raisons les plus souvent évoquées étaient la faiblesse générale, la souffrance liée au désespoir et la perte de dignité.

La perte de dignité était clairement plus souvent évoquée comme raison lors de demandes d´euthanasie que lors de demandes d´ arrêt d´un traitement médical.(Chapitre 3).

L´aggravation des symptômes durant les derniers mois de vie était particulièrement importante parmi les patients ayant fait une requête pour ESA. Il semble que la souffrance physique accompagnée par des problèmes psychosociaux et des préoccupations mène plus singulièrement à des demandes pour ESA (Chapitre 3).

Les patients mort après EAS avaient à la fin de leur vie plus de plaintes de douleur, de vomissement, de nausée, de toux, et de sentiments de malaise général que les patients n´ayant pas faits de demande pour ESA (Chapitre 4). Les résultats indiquent qu´ íl n´y avait pas de différence entre le traitement et les soins de patients ayant fait une demande pour ESA et de patients n´ayant pas fait une telle demande. Les résultats de cette recherche indiquent que les demandes pour euthanasie et suicide assisté n´émanent pas de soins terminaux défaillant mais plutôt de la souffrance du patient (Chapitre 4).

Les proches de patients mort après EAS décrivent que l´euthanasie ou le suicide assisté ont surtout contribués à la qualité de fin de vie du patient par la diminution de la durée de la souffrance et par le respect des derniers souhaits du patient (Chapitre 5).

*Expériences des médecins concernant le soins de fin de vie et les décisions médicales en fin de vie.*

La plupart des médecins soulignent l´ importance de la qualité des soins de fin de vie et de développements concernant les soins terminaux (Chapitre 6 et Chapitre 7). Certains médecins affirment aussi que par une qualité de soins de fin de vie optimale il est moins nécessaire de recourir à l´euthanasie ou au suicide assisté.

Les médecins décrivent fréquemment que l´ESA sont des interventions de derniers recourt, employés quant il n´est plus possible par d´autres moyens d´alléger la souffrance du patient (Chapitre 6). Les médecins exprimaient des sentiments bien plus ambigus face aux décisions concernant l´ESA que face a des décisions concernant l´ arrêt de traitements médicaux.

Les interviews avec les médecins de famille montrent clairement que ces derniers se sentaient fortement accablés face aux demandes pour ESA de patients en face terminale (Chapitre 3 et Chapitre 6). Avoir a prendre une décision à propos d´une demande pour ESA était décrit comme une expérience très exigeante.

La souffrance du malade et les propres convictions du médecins à propos des soins palliatifs et de l´autonomie du patient guidaient le médecin lors de ces décisions. Leurs convictions et leurs habilitée a accepter leur participation et implication dans une situation d´ euthanasie étaient des éléments essentiels de leur attitude face à des demandes pour ESA. Certains médecins de famille soulignaient l´importance s´assurer une mort douce et surtout de traiter les symptômes du patient plutôt que de devoir faire face a une demande d´euthanasie, d´autres soulignaient l´importance de développer leurs habilitées a soigner les patients en phase terminale de maladie et de pouvoir contribuer à la qualité de vie des patients. Certains médecins expliquaient que quand il n´y avait aucune autre alternative ils étaient prêts a surpasser leurs propres convictions afin de pourvoir à une demande d´ESA et ainsi de pouvoir répondre à la souffrance du patient (Chapitre 6)

Les médecins semblent avoir une position nuancée vis a vis de ESA aux Pays-Bas. Bien que croyant dans les possibilités d´amélioration des soins de fin de vie, ils considèrent que par les soins palliatifs il n´est pas possible de diminuer toutes formes de souffrance et donc que l´euthanasie ou le suicide assisté médicalement peuvent être appropriés dans certains cas.

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Jean-Jacques Georges obtained his Master degree in Health Sciences, specialisation Nursing science at Maastricht University in 1998. He worked from 2001 to 2005 at the VU University Medical Center in Amsterdam, EMGO institute as a junior researcher. He is currently working at the Hogeschool Utrecht (HU), Faculty of Health Care, department of Nursing studies as a teacher .

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# Appendix

b

# Questionnaire to be completed shortly after the death of the patient

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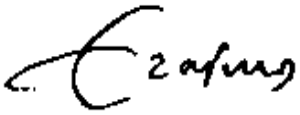
VU medisch centrum



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Geneeskundig Onderzoek

Erasmus Universiteit,
Rotterdam Instituut
Maatschappelijke
Gezondheidszorg

# Questionnaire:
# after the death of the patient

**Date on which the questionnaire was completed**

Day - month

This questionnaire concerns the medical situation of a patient with cancer for whom no further curative treatment was possible and about whom you have already answered some questions. You gave the following code to the patient. We advised you to make a note of this code in the patient's files.

From the interview it appears that when you answered the questions you had seen the patient the last time on [date] … …..

This date will be included in some of the questions in order to make it clear which period of time the questions refer to .

**Information about the questionnaire**

This questionnaire concerns the situation of the patient before he/she died. It will take you 5-10 minutes to answer the questions. We ask you to complete this questionnaire soon after the death of the patient.

Please indicate the answer that is close to the actual situation.

In such a short questionnaire it is obviously not possible to describe in detail the situation and the decision making process related to a seriously ill patient.

Whenever you wish to add more information about your answers, you can make use of the space at the end of the questionnaire.

Instructions for completing the questionnaire:

- use a bio (not a fountain pen or a fine liner)
- put a cross inside the box only
- correct any mistakes by filling in the whole box and than putting a cross inside the correct box.

1 When did the patient die?(date)

*Day / month*

2 How often have you seen the patient since ……?

*Number of visits*

3 When did you see last the patient? *(date)*

Day / month

4 At that time, how many days/ weeks did you think the patient would live ?

*Days*

*Weeks*

5 Did any severe complications occur since ……..?

☐ No

**go to question 7**

☐ Yes

6 Please describe these complications?

7 For each of the following symptoms and complaints, could you please indicate on a 5-point scale the degree to which they were applicable to the patient's situation in spite of any treatment, when you saw the patient for the last time?

| **Physical domain** | **1** | **2** | **3** | **4** | **5** | |
|---|---|---|---|---|---|---|
| No pain | □ | □ | □ | □ | □ | Severe pain |
| No pressure ulcers | □ | □ | □ | □ | □ | Severe pressure ulcers |
| No nausea | □ | □ | □ | □ | □ | Severe nausea |
| No vomiting | □ | □ | □ | □ | □ | Severe vomiting |
| No coughing | □ | □ | □ | □ | □ | Severe coughing |
| No dyspnoea | □ | □ | □ | □ | □ | Severe dyspnoea |
| No problems with swallowing | □ | □ | □ | □ | □ | Severe problems with swallowing |
| No dry mouth | □ | □ | □ | □ | □ | Severe dry mouth |
| No loos of appetite | □ | □ | □ | □ | □ | Severe loss of appetite |
| No problems with sleeping | □ | □ | □ | □ | □ | Severe problems with sleeping |
| No constipation | □ | □ | □ | □ | □ | Severe constipation |
| No urinary incontinence | □ | □ | □ | □ | □ | Severe urinary incontinence |
| No faeces incontinence | □ | □ | □ | □ | □ | Severe faeces incontinence |
| No unattractive odour | □ | □ | □ | □ | □ | Very unattractive odour |
| No fatigue | □ | □ | □ | □ | □ | Severe fatigue |
| No dependency in daily activities | □ | □ | □ | □ | □ | Total dependency in daily activities |
| Feeling well | □ | □ | □ | □ | □ | Feeling unwell |

| **Psychosocial domain** | **1** | **2** | **3** | **4** | **5** | |
|---|---|---|---|---|---|---|
| No coping problems | □ | □ | □ | □ | □ | Severe coping problems |
| Not confused | □ | □ | □ | □ | □ | Very confused |
| Conscious | □ | □ | □ | □ | □ | Unconscious |
| Not depressed | □ | □ | □ | □ | □ | Severely depressed |
| Not anxious | □ | □ | □ | □ | □ | Very anxious |
| No feelings of guilt | □ | □ | □ | □ | □ | Severe feelings of guilt |

| | | | | | | |
|---|---|---|---|---|---|---|
| No feelings of guilt | ☐ | ☐ | ☐ | ☐ | ☐ | Severe feelings of guilt |
| No feelings of loneliness | ☐ | ☐ | ☐ | ☐ | ☐ | Severe feelings of loneliness |
| No feelings of powerlessness | ☐ | ☐ | ☐ | ☐ | ☐ | Severe feelings of powerlessness |
| No problems with dependency | ☐ | ☐ | ☐ | ☐ | ☐ | Severe problems with dependency |
| No feeling of meaninglessness | ☐ | ☐ | ☐ | ☐ | ☐ | Severe feelings of meaninglessness |

8 Was the patient receiving a medical treatment for the following symptoms <u>when you last saw him/her</u> :

*If so, was it an existing treatment that was continued and/or adapted, or was it a new treatment for a certain complain?*

| | Yes, existing treatment was continued or adapted | Yes, new treatment started | No |
|---|---|---|---|
| Pain | ☐ | ☐ | ☐ |
| Nausea | ☐ | ☐ | ☐ |
| Dyspnoea | ☐ | ☐ | ☐ |
| Depression | ☐ | ☐ | ☐ |
| Anxiety | ☐ | ☐ | ☐ |
| Confusion | ☐ | ☐ | ☐ |
| **Other, such as:** | | | |
| *1)* | ☐ | ☐ | ☐ |
| *2)* | ☐ | ☐ | ☐ |
| *3)* | ☐ | ☐ | ☐ |
| *4)* | ☐ | ☐ | ☐ |
| *5)* | ☐ | ☐ | ☐ |

9 Which disciplines were involved in treating or caring for the patient when you last saw him/her?

| | Yes | No | Do not know |
|---|---|---|---|
| Internist / oncologist | ☐ | ☐ | ☐ |
| Radiotherapist | | | |
| Pain specialist | ☐ | ☐ | ☐ |
| Neurologist | | | |
| Surgeon | ☐ | ☐ | ☐ |
| Palliative care consultant/consultation team | | | |
| Psychiatrist / Psychologist | ☐ | ☐ | ☐ |
| Nurse | | | |
| Wound consultant / Stoma nurse | ☐ | ☐ | ☐ |
| Home care technology specialist | ☐ | ☐ | ☐ |
| Intensive home care provider | ☐ | ☐ | ☐ |
| Social worker | ☐ | ☐ | ☐ |
| Physiotherapist / ergotherapist | ☐ | ☐ | ☐ |
| Dietician | ☐ | ☐ | ☐ |
| Pastor/ spiritual advisor | ☐ | ☐ | ☐ |
| Alternative healer | ☐ | ☐ | ☐ |
| Volunteer | ☐ | ☐ | ☐ |
| *Other:* | ☐ | ☐ | ☐ |

10 Were there relatives or other people in the patient's environment who were involved in caring for the patient <u>when you last saw him/her</u>? If so, who?

| | Yes | No | Don't know |
|---|---|---|---|
| ☐ Partner | ☐ | ☐ | ☐ |
| ☐ Parent(s) | ☐ | ☐ | ☐ |
| ☐ Child(ren) | ☐ | ☐ | ☐ |
| ☐ Other relatives | ☐ | ☐ | ☐ |
| ☐ Friends/neighbours | ☐ | ☐ | ☐ |
| ☐ Other: | ☐ | ☐ | ☐ |

11 Did the patient realise, <u>when you last saw him/her</u>, that he/she was terminally ill, respectively that he/she would probably die soon?

☐ Yes, the patient realised he/she was terminally ill and would probably die soon

☐ Yes, the patient realise he/she was terminally ill, but not that he/she would probably die soon

☐ No, the patient did not realise that he/she was terminally ill

☐ Don't know

12 Did the patient has mentioned since …….. that he/she was concerned about one or more of the following subjects?

- ☐ Pain
- ☐ Dyspnoea
- ☐ Confusion
- ☐ Unconsciousness
- ☐ Dependency on others for personal care
- ☐ Dependency on medical technology
- ☐ Addiction to pain-killers or others type of medication
- ☐ Missing an (important) event
- ☐ No longer able to communicate
- ☐ Loneliness
- ☐ Loss of dignity
- ☐ Fear of death
- ☐ Fear of the dying process
- ☐ Other.: ☐

13 Did the patient express any of the following wishes about end-of-life medical treatment since …….?

| | | Yes | No |
|---|---|---|---|
| *1)* | Forgoing any further life prolonging treatment | ☐ | ☐ |
| *2)* | Heavy sedation until death | ☐ | ☐ |
| *3)* | Euthanasia or assisted suicide at a <u>later stage</u> | ☐ | ☐ |
| *4)* | Euthanasia or assisted suicide <u>in the near future</u> | ☐ | ☐ |

**If the patient did not express any of these wishes after the date mentioned , please go to question 26**

**The following questions (14 t/m 23) concern the last answer of 'Ýes' to question 13, i.e. about the request/wish with the highest number between brackets in front of the answers categories**

14 What were the most important reasons for the patient to express this wish?

- ☐ Degradation/loss of dignity (1)
- ☐ General weakness/fatigue (2)
- ☐ Fatigue after prolonged medical treatment (3)
- ☐ Tired of life (4)
- ☐ Meaningless suffering (5)
- ☐ Hopeless suffering (6)
- ☐ Pain (7)
- ☐ Vomiting/nausea (8)
- ☐ Dyspnoea (9)
- ☐ Fear of suffocation (10)
- ☐ Fear of pain (11)
- ☐ Fear of the dying process (12)
- ☐ Threat of complications (13)
- ☐ Invalidity/immobility (14)
- ☐ Dependency (15)
- ☐ Not becoming a burden on others (16)
- ☐ Experience of deterioration among friends/family(17)
- ☐ Loss of control over own life (18)
- ☐ Other: (19)

☐

15 Which of these reasons was the most important? Fill in the number of the most important reason (numbers are between brackets after each answer category in question **14**)

☐

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16 Do you think that the patient, when he/she expressed this wish was fully aware of his/her situation and competent enough to make such a decision?

- ☐ Yes, fully aware **(go to question 18)**
- ☐ No, not fully aware
- ☐ No, not competent at all

17 Why do you think that the patient was not (fully) competent?

- ☐ Because of the effects of medication
- ☐ Patient was delirious
- ☐ Patient was too young
- ☐ Patient was not conscious
- ☐ Patient was dement
- ☐ Patient was mentally handicapped
- ☐ Patient had a psychiatric disorder
- ☐ Other: ____

18 To what extent could you understand the patient's wish?

☐ Very well ☐ Quite well ☐ Moderately ☐ Not at all

19 Did you (or one of your colleagues) grant the patient's wish ?

☐ Yes, because

Indicate below the reasons why the wish was granted and then go to **question 20**

- ☐ Suffering was unbearable
- ☐ Suffering was hopeless
- ☐ Quality of life was low
- ☐ No hope of any improvement
- ☐ Any further treatment was meaningless
- ☐ Treatment was withdrawn but the patient did not die
- ☐ Relatives could not longer cope with the situation
- ☐ Economical reasons played a role (e.g. lack of beds)
- ☐ Other: ____

☐ No, because

Indicate below the reasons why the wish was not granted And then go **question 21**

- ☐ Suffering was not unbearable
- ☐ Suffering was not hopeless
- ☐ Patient was depressed
- ☐ Treatment options were still available
- ☐ Patient was not fully aware of his/her situation
- ☐ Request was not well-considered/persistent
- ☐ Patient died before decision could be made
- ☐ Request was influenced by relatives
- ☐ Objection in this specific case
- ☐ Never perform euthanasia or assisted suicide
- ☐ Other: ____

20 In your opinion, to what extent was the patient's life shortened because the patient request was granted?

- ☐ More than 6 months
- ☐ 1 – 6 months
- ☐ 1 – 4 weeks
- ☐ No longer than 1 week
- ☐ Less than 24 hours
- ☐ Probably did not shorten the patient's life at all
- ☐ Other:

21 If you look back on the situation, do you think that the way in which you reacted to the last-mentioned wish resulted in an improvement in the quality of the end of the patient's life?

☐ Yes, very much ☐ Yes, somewhat ☐ Scarcely ☐ Not at all ☐ Don't know

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22 Do you, in retrospect, have any doubts about the way in which you reacted to the (last-mentioned) wish of the patient?

☐ Yes, many ☐ Yes, some ☐ No, none at all

23 Could you describe how was you experienced the way in which you reacted to the last-mentioned wish of the patient?

- ☐ Satisfying
- ☐ Feelings of relief
- ☐ Heavy responsibility
- ☐ Burdensome
- ☐ Unnatural
- ☐ Other:

24 Do you think- in retrospect – that the patient has receive the care he needed?

☐ Yes ➔ **go to question 26**

☐ No, insufficient:

- ☐ Medical care
- ☐ Nursing care
- ☐ Psycho-social care
- ☐ Home keeping care
- ☐ Mental/spiritual care
- ☐ other:

25 Do you think that the above-mentioned lack of care influenced the patient to make the last-mentioned request?

☐ Yes ☐ No ☐ Don't know

26 To what extent do the following statements apply to the death of the patient?

| | **Fully** | **Somewhat** | **Not at all** |
|---|---|---|---|
| The patient died quietly and peacefully | ☐ | ☐ | ☐ |
| The patient was able to say good-bye to his/'her relatives before he/she died | ☐ | ☐ | ☐ |
| The patient was ready to die | ☐ | ☐ | ☐ |
| The patient died suddenly and unexpectedly | ☐ | ☐ | ☐ |
| The patient went through a period of unrest before he/she died | ☐ | ☐ | ☐ |
| The patient became unconscious before he/she died | ☐ | ☐ | ☐ |

27 If you wish to provide more information about certain answers, do so on this space

**Please send the completed questionnaire back as soon as possible in the enclosed envelope**

**Thank you for your co-operation**

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